

**Cancer Caregivers: Here & Now**  
**Brief Group Social Work Intervention for**  
**Caregivers of People with a Life Threatening Illness**

**By Ruth Elaine Zetner**

**A Practicum Report Submitted to the Faculty of Graduate Studies**  
**In Partial Fulfillment of the Requirements for the Degree of**  
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Caregivers of People with a Life Threatening Illness**

**BY**

**Ruth Elaine Zetner**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree**

**of**

**MASTER OF SOCIAL WORK**

**RUTH ELAINE ZETNER ©2002**

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### Dedication

This work is dedicated to the memory of my parents, Charleen H. Bauer and Stanley A. Bauer, who taught me about life through their living and their dying.

This work is also dedicated to the memory of Ellen M. Tabisz. She inspired me as a woman and as a social worker. I will hold her example of a life lived fully and meaningfully as a benchmark for my own.

## Abstract

**This practicum report describes the social work brief group intervention designed to address the concerns of family caregivers of people with a life-threatening illness. It was an identified gap in the palliative care service provided to family caregivers in Winnipeg, Manitoba. A literature review explores the current perspective on anticipatory grief, the needs of family caregivers, the therapeutic value of group intervention, value and use of co-facilitators, the palliative care philosophy, and, the preventative value of responding to family caregivers' needs prior to the death of their loved ones. The development and experience of the brief group intervention is presented with the survey results and participants' responses to corroborate the effectiveness of this intervention as concluded by the practicum student. As well there is a discussion of the insights gained while working with this population of people and recommendations for future social work intervention with family caregivers of people with a life-threatening illness in palliative care.**

## Chapter One

### Practicum Focus

This practicum consisted of two brief social work group interventions offered for caregivers of people with a terminal illness. Each group lasted five weeks and was offered in afternoons from 4-5:30 p.m. The groups were co-facilitated with another social worker. The location was a room made available at St. Boniface General Hospital.

The focus of this practicum developed from concern for the family caregivers who are involved with someone with a terminal illness. Dr. H.M. Chochinov (1997) outlined his research about the relationship between pain control and the will to live in people receiving palliative care. He indicated that the person's "will to live" had an inverse relationship with the amount of experienced pain. The research showed that when the experience of pain was high the "will to live" was low, and the reverse was true. Dr. Chochinov outlined the effort to relieve an individual's pain and the benefits to his/her experience of living until he/she died. The concept of the family caregiver's pain and how it needs to be similarly managed by professional caregivers was evident in his presentation. Thoughts about the existential pain of family members throughout the palliative process occurred to the writer. The incubation of these thoughts and about the therapeutic interventions offered to families at this time in their lives provided the foundation for this practicum.

The wellbeing of the family influences the patient's sense of worth, integrity and identity (Rando, 1984). Recent research confirms that poor health affects relationships, that interpersonal variables have an impact on health, and that adaptation to stressful events (e.g. life threatening illness) may be facilitated by adequately provided social support (Baider, Koch, Esacson & De-Nour, 1998). Bowen (1991) presented the association between the family's functional level and their emotional reaction to the terminal illness of a loved one, based on his/her importance within the family system. In view of this association, the focus of the practicum was chosen.

A brief community services review determined that there are no therapeutic groups available to family caregivers of people with a terminal illness. In conversations with professional caregivers at various facilities (Hospice & Palliative Care Manitoba, St. Boniface Palliative Care Unit, CancerCare Manitoba, Breast Health Centre, Riverview Health Centre - Palliative Care Unit, and Hope Breast Cancer Information & Resource Centre), there was a sense of agreement to the need for such a group to offer supportive intervention to caregivers in anticipatory grief.

The rationale for providing group social work intervention for family members of the terminally ill is based in hospice philosophical assumption and principles which state that "the care of the dying is a process involving the needs of the patient, family and caregivers" (Rando, 1984, p. 293). The associated principle is "the interaction of these three groups of individuals must constantly be assessed

with the aim being the best possible care of the patient. This cannot be accomplished if the needs of family and/or caregiver are negated” (Rando, 1984, p. 293).

The group therapy modality was chosen in recognition of the curative factors of a group. It is anticipated that the caregivers participating would benefit by gaining a sense of universality, a cathartic experience with the existential factors of coming to terms with reality, and a broader perspective and acceptance of life in its fullness (Toseland & Rivas, 1998).

The short-term group method serves a purpose. Its time limited nature “elicit[s] powerful existential issues as the members begin to think about where they are in their lives, the time still remaining to pursue their goals, and the fact that they must get a move on” (Klein, 1993, p. 259). The structure is suited to issues such as loss, developmental life tasks and family issues. The brief therapy mode can provide the participants with an emotionally powerful learning experience to respond to those life issues and areas of conflict (Klein, 1993). This style acknowledges that there are many demands on family caregivers’ time, necessitating a compact therapeutic experience in which to maximize the anticipated benefits (Drum & Knott, 1977).

### Rationale

The news of a person having a terminal illness is felt throughout the circle of family members and friends. Therese Rando (1984), in *Grief, Dying and Death*,



states that “grief is the process that allows us to let go of that which was and be ready for that which is to come” (p. 17). Indeed, it is thought that “the grief work of individuals and families is inextricably linked, insofar as the two processes are not only overlapping, but reciprocally interactive”(Moos, 1995).

In the current social work view of the family as a system, what happens to an individual member has an impact on the family as a whole (Nichols & Schwartz, 1998; Rando, 1984). The type of family system, whether it is open and flexible or closed and rigid, will determine the need for intervention when assessed by professional caregivers (Rando, 1984; Walsh & McGoldrick, 1991). Families that are able to adjust to changes have relaxed role assignments and open, direct communication patterns, are more able to function under duress. In contrast families with a closed style of communication, highly dependent on one another, very role defined and entrenched, are likely to require extensive professional caregiver support (Bowen, 1991; Greene & Kropf, 1995; Rando, 1984).

Terminal illness in a family causes disruptions in the family’s homeostasis and makes the family vulnerable to stress. The disruption begins at the diagnosis of a terminal illness of a loved one (Rando, 1984). This stress reaction is amplified by the structures of our current society, which typically have extended family members isolated from each other, living in different locations (Walsh & McGoldrick, 1991). Due to this situation, the traditional family member’s supportive roles are ascribed to society (Rando, 1984). Consequently, professional caregiver involvement is recommended for the family in an effort to support them and the person with

terminal illness (Heller & Roccoforte, 1997; Hills, 1998; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996; Rando, 1984).

From the family systems perspective the grief process involves the deceased and the survivors in the circle of life by affirming the finality of death and the continuity of life (Walsh & McGoldrick, 1991). However in our death defying and denying society, life affirming rituals which accept death as part of life are diminished (Rando, 1984). Division of nuclear families through urbanization, secularization of beliefs, and medical knowledge which sustains life beyond the natural life cycle, all contribute to the difficulty families experience with the death of a loved one (Rando, 1984).

The individual process of grief is determined by the personality of the grieving person, the relationship with the person who died, and the social context of the death (Roach & Nieto, 1997). The experience of someone's death is considered the most difficult adjustment to make in a person's life (Walsh & McGoldrick, 1991). Indeed, it is crucial to mourn as an individual and within the family process (Paul & Grosser, 1991; Rando, 1984; Walsh & McGoldrick, 1991).

Elizabeth Kübler-Ross wrote *On Death and Dying* (1973) to describe what emotions that she had observed in people prior to their death. She presented five stages for responding to dying and death; denial and isolation, anger, bargaining, depression and acceptance. Although these stages simplify a complex process, they do provide a framework for understanding the emotional movement throughout the final stage of life. This pioneer work broke the silence surrounding the dying

process and exposed the need for social work intervention in the lives of people who are dying and their family.

The conventional grieving process within the family is partially determined by the transgenerational family experience of illness and death (Bowen, 1991; Rolland, 1991; Walsh & McGoldrick, 1991). If the family's belief system includes death as a natural phenomenon to respond to as a family, then the current grieving person will have a positive role model. However, if the previous experience of illness and death in the family resulted in a great disturbance, that family will not be well equipped to manage. In fact, it has been determined that within a grieving family, there are an increased number of children in trouble at school, adults committing adultery or requiring medical attention (Bowen, 1991; Paul & Grosser, 1991; Walsh & McGoldrick, 1991). These factors all contribute to the positive adjustment or to the challenges of reclaiming a life without a loved one in bereavement (Kutscher, 1973; Paul & Grosser, 1991; Rolland, 1991).

The anticipatory grief process begins when a loss is anticipated. It is a path of adjustments, a psychosocial, physical and spiritual reorganization that occurs when someone you love has a terminal illness (Gilliland & Fleming, 1998; Rando, 2000). As an individual process done within a family, its expression is determined by the individual's relationship to the loved one, and, the cultural, familial and historical factors which affect their reactions (Rolland, 1991; Walsh & McGoldrick, 1991).

Anticipatory grief evolves with the disease process and is not as well recognized as conventional grief. It is a parallel process, experienced by the dying person as well as by their family and friends (Gilliland & Fleming, 1998; Kutscher, 1973; Rando, 1986; Rando, 2000). It is a complex process, which involves a different focus of grieving for the dying individual and for his/her family (Kutscher, 1973; Roach & Nieto, 1997). As the complexities of anticipatory grief emerge, the sensitivity of professional health care providers is essential (Gilliland & Fleming, 1998; Kristjanson, et al., 1996; Rando, 1986; Rolland, 1991; Wilson & Daley, 1999).

The work of anticipatory grieving affects how a person lives until he or she dies, as well as how a family perceives the dying process and grieves the subsequent death of their loved one (Attig, 2000; Byock, 1997; Kristjanson et al., 1996; Lamers, 2000; Rando, 2000). The complicated process of living fully in the moment requires opportunities for the complete expression of thoughts and feelings, to resolve any issues within the relationship in preparation for the loved one's death (Byock, 1997; Lamers, 2000)

The role of being a family caregiver has been presented as a stressful, significant process, and a complex experience (Byock, 1997; Kristjanson et al., 1996; Lamers, 2000; Rando, 2000). It requires the family to manage their regular life responsibilities (e.g. work, children, pets, home maintenance, etc.) as well as be the care manager for their loved one with the terminal illness (e.g. doctor, nurse or social worker appointments, home care attendants, etc.) (Bowen, 1991; Roach & Nieto, 1997; Rolland, 1991).

A family caregiver provides an essential link for the professional caregivers to the person with a terminal illness (Kristjanson et al., 1996; Lobchuk & Stymeist, 1999; Rando, 1984; Roach & Nieto, 1997). She/he can provide insight into the family belief system, experiences with loss and interpret symptom expression in a meaningful manner (Lobchuk & Stymeist, 1999). Moreover, studies have indicated that when a family caregiver's wellbeing is nurtured by the professional caregivers, the health and sense of worth of the terminally ill person is influenced (Rando, 1984).

### Intervention Goals & Learning Goals

The practicum explored the effectiveness of group therapy on this population and evaluated the needs, practicality of the provision of services and the benefits of this method of social work intervention on family caregivers. The evaluation of the intervention was limited to gleaning information from this group of people through a post group satisfaction survey. The overall goal was that family caregiver support groups would relieve the intensity of acute symptoms related to anticipatory grief (Gilliland & Fleming, 1998; Rolland, 1991). Four sub-goals were created to focus attention on the weekly activity within the groups and evaluate the progress. These goals were:

1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.

2. To engender confidence within the family members, to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.
4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people.

Also these groups were expected to facilitate later benefits for the bereaved in that the intervention was anticipated to increase their ability to cope with past, present and future losses associated with the death of their loved one. This expectation is difficult to formally evaluate and is beyond the scope of this practicum (Bowen, 1991; Gilliland & Fleming, 1998; Paul & Grosser, 1991; Rolland, 1991).

Additional understanding of participants' satisfaction was expected to enhance the profession's understanding of the needs of caregivers in anticipatory grief. The practicum student was evaluated through the use of weekly audiotapes, supervision discussions with practicum advisor Dr. Brenda Bacon, with the co-facilitator Ms Ela Minaker, after each group, and through feedback from the group members. The student reflected on her skill development and experiences in a journal that was discussed in supervision. There were five learning goals for the practicum student as reference for her development in this experience. They were:

1. To develop skills as a social worker leading groups.

2. To develop a comfort level with the narrative therapeutic approach of intervention within a group context.
3. To explore the experiential approach within a group setting.
4. To work with a co-facilitator within a group setting.
5. To learn directly from caregivers of people with a life threatening illness about their stresses and needs.

At the end of the five weeks, the participants completed a client satisfaction survey. It was a brief survey with nine questions, six were answered with a five point Likert scale and three were short answers (Appendix H). This survey formally received their comments about their experiences. Although the results of these surveys are not statistically significant from a research perspective, not a cross-section of people etc., they were received as authentic feedback from these family caregivers as an indication of the worth of this intervention. As well, in the final session the experiential activity sheet created an opportunity for written comments to the co-leaders of the group. This information was used to draw concluding remarks and to derive recommendations for future social work intervention in the effort to meet the needs of family caregivers in anticipatory grief.

## Chapter Two

### Literature Review

The following literature review will expand on the information related in the introduction to the practicum. It will give definition to anticipatory grief and contrast it with conventional grief, as well as defining the population of caregivers and their importance within the health care team involved in a terminally ill person's care. The type of group intervention and therapeutic approach will also be outlined. This combination of information will support the practicum purpose.

### Grief

#### Conventional Grief

Throughout history conventional grief has been managed with various cultural mourning rituals based in their religious beliefs (Rando, 1984; Roach & Nieto, 1997; Walsh & McGoldrick, 1991). It is responded to by every society (Rando, 1984; Walsh & McGoldrick, 1991). In primitive societies death was viewed within the life cycle and it was more accepted with the use of rituals (Rando, 1984). Recent times have shown North Americans to be death denying in their efforts to distance themselves from the dying process (Walsh & McGoldrick, 1991). Many people die in hospitals or personal care homes isolated from their family and familiar surroundings. The combination of urbanization and secularization of



society has contributed to the changes in conventional grief and how it is recognized within families (Rando, 1984).

Grief is an individual process which is dynamic, pervasive and common (Roach & Nieto, 1997). Conventionally, grief is recognized after the death of a person. However, grief can be experienced at many points within the family. Examples of other times are when a child is born with disabilities, or when a family experiences the separation and divorce of a couple (Paul & Grosser, 1991; Rando, 1984; Rolland, 1991; Walsh & McGoldrick, 1991). The common element of these experiences in a family life cycle is loss, how the family homeostasis is disrupted and how it is resolved (Bowen, 1991; Paul & Grosser, 1991; Rando, 1984; Rolland, 1991; Walsh & McGoldrick, 1988).

When Kübler-Ross (1973) introduced the five stages of grief, she facilitated the movement of research into death and dying. Her work became a catalyst for changing people's understanding of grief. Researchers refer to Kübler-Ross' work as a beginning point in the advent of new thoughts about grieving losses (Rando, 1984). The stages of adjustment to loss have helped clarify and de-mystify the emotional process prior to and after someone's death.

Grief brings out past issues and unresolved conflicts each time it occurs in a family. A sense of helplessness and being out of control exacerbates the psychological resources of the individual when he/she is grieving a loss (Rando, 1984). An individual's coping ability will have a functional or dysfunctional consequence within a family system (Walsh & McGoldrick, 1991). It will affect the

“emotional underground network of emotional dependency of family members on each other”(Walsh & McGoldrick, 1991, p. 4). The ability or inability to cope with a loss is not only a reflection on the individual but is also a result of a family process. An individual’s or family’s response to loss can be blocked by unresolved past losses (Rando, 1984; Walsh & McGoldrick, 1991).

### Anticipatory Grief

In 1944, Eric Lindemann first recognized the concept of anticipatory grief, when he presented it as a unique separation syndrome (Gilliland & Fleming, 1998). Anticipatory grief is as challenging and painful as a death for the family (Rolland, 1991) and is viewed by professional caregivers as having a more intense level of acute responses than conventional grief (Gilliland & Fleming, 1998). In 1986, Rando expanded the definition of anticipatory grief to include past and current losses as well as future ones. Her proposed definition of anticipatory grief is:

The phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future... anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying patient.

(p. 24)

Tasks associated with anticipatory grief include adjustments to loss similar to those of conventional grief (Rando, 1984). There is an avoidance phase of disbelief, shock and anger, then, a confrontation phase of acute, highly charged emotions related to the diagnosis and the anticipated loss of a loved one. Included in the process of anticipatory grief for the family is the witnessing of the decline of health of their loved one (Walker, Pomeroy, McNeil, & Michaelin 1994). In the final stage of re-establishment, the acute grief reaction declines and the individual begins to cope with everyday social responsibilities of life (Lamers, 2000; Rando, 1998). This process is likened to a ride on a roller coaster, with the fluctuations of hope and pain (Roach & Nieto, 1997).

The recognition of anticipatory grief facilitates the process of the individual's and family's adjustment to the terminal illness (Rando 1986; Walker et al., 1994). Anticipatory grief is a multidimensional experience involving physical, cognitive, emotional, social and behavioural features and symptoms (Gilliland & Fleming, 1998; Rolland, 1991; Walker et al., 1994). The tasks associated with this adjustment period are complex and if left unresolved or unrecognized these complexities greatly influence the individual's and family's ability to cope with the impending losses (Davies, 2000; Rolland, 1991; Rando, 1986; Walsh & McGoldrick, 1991).

### Conventional vs Anticipatory Grief

Conventional grief is a well-documented phenomenon (Kübler-Ross, 1969; Rando, 1984; Roach & Nieto, 1997; Walsh & McGoldrick, 1991) but anticipatory

**grief is not as well recognized (Gilliland & Fleming, 1998; Paul & Grosser, 1991; Rando, 1984). There is limited understanding about its occurrence, in part due to the ethical dilemmas of research at such a poignant time in a family's life (Gilliland & Fleming, 1998). An alternative perspective is that it is unethical to provide any kind of service at this sensitive time without conducting a study to determine whether it is beneficial (Parkes, 1995). Within this perspective, the family caregivers attending to a terminally ill person are not considered to be as vulnerable as when they are in bereavement.**

**Bowen (1991) suggested that part of the reason for the dearth of literature regarding anticipatory grief has more to do with the death denying factors of the professional caregivers. This perspective is supported by others (Fleming, 2000; Kübler-Ross, 1973; Kutscher, 1973; Zilberfein, 1999) who reflect on the need for professional caregivers to be comfortable with their own mortality and personal experiences with death before embarking on professional interventions with others.**

**The limited acknowledgement and study of anticipatory grief represents a doorway to improving professional intervention with people who are terminally ill and their families. Indeed, anticipatory grief is considered to have a more intense level of acute responses than does conventional grief (Gilliland & Fleming, 1998). This type of grief is a parallel grieving process for the dying person and the family members (Kutscher, 1973; Rando, 1984; Rolland, 1991). This intense period of time for families is further complicated by limited social supports, pre-existing**

stress and the desire to “appear strong” for the benefit of the person who is ill (Gilliland & Fleming, 1998).

If memories and thoughts surrounding the deceased arouse feelings of guilt, anxiety, depression, or pronounced feelings of relief and triumph, it is difficult to speak of resolution of the loss and relations with the deceased. If, however, the memories and thoughts are available in a balanced fashion and provide a measure of strength, warmth, and solidarity to the core experience of the bereaved, it is appropriate to think of resolution of the loss (Rubin, 1999, p. 692).

The advancement of medical practice has extended the period of anticipatory grief and has broadened the function of this period of adjustment (Roach & Nieto, 1997). For the individual as well as the family, anticipatory grief is the process that allows the reality of the pending loss to be absorbed. It is the opportunity to affirm relationships, to resolve unfinished conflicts, and to make plans for the future (Roach & Nieto, 1997). Anticipatory grief is experienced as a combination of past, present and future losses associated with terminal illness rather than as only in anticipation of the death (Gilliland & Fleming, 1998).

### Anticipatory Grief in the Dying Person

A few generations ago death was viewed as a natural phenomenon of life (Buchanan, 1984). Now the focus of modern medicine is to prolong life without ever concentrating on the ultimate side effect of disease, dying and death (Lamers, 2000). One of the drawbacks of the current society’s focus on life-prolongation is the

fact that an individual may not be defined as “dying” until it is too late for him/her to have enough quality time to prepare psychologically, spiritually and socially (Lamers, 2000). Consequently when a person becomes diagnosed with a terminal illness, there is a very complicated and stressful response which is interwoven with his/her family and professional caregivers (Buchanan, 1984). The dying person experiences the fullness of grief in addition to his/her physical illness.

The individual’s dying process has been referred to as “disidentification” which reflects the withdrawal from work, family life, meaningful activities, and events (Lamers, 2000). The process of dying is a taboo experience not easily spoken about in the general population or with professional caregivers who sometimes become “immune” to the various effects of the person’s condition (Buchanan, 1984). As a result, the practical daily actions of physically caring for the dying person, takes precedence over their need to discuss their hopes, fears, spiritual concerns and issues related to dying (Buchanan, 1984; Davies, 2000; Lamers, 2000).

The dying individual is anticipating many losses and grieves them all. They include the loss of previous levels of functioning; loss and functioning of body parts; loss of anticipated future with loved ones; loss of hopes, dreams and their relationships with friends and family; and, the loss of the sense of personal invulnerability (Lamers, 2000; van Bommel, 1989). Unlike conventional grief, which diminishes over time, the anticipatory grieving process of the dying individual continues to expand until death (Lamers, 2000).

The dying person's response is dependent upon his/her position in the life cycle. It is different for an older person than a younger one. As a person ages his/her concept of death and dying will evolve and affect how they perceive terminal illness and the dying process (Lamers, 2000; Rando, 1984). Dying brings into focus a myriad of emotions including shame, guilt, anger, depression, loneliness, and fear (Rando, 1984; van Bommel, 1989). These emotions fluctuate with the dying process, the physical changes, the level of pain, and how it is managed (Chochinov, Tataryn, Clinch, & Dudgeon, 1999; Lamers, 2000).

In his book, "Caregiving: Hospice-Proven Techniques for Healing Body & Soul", Smith (1997) composed "A Bill of Patient's Rights." These rights included

- The right to be in control.
- The right to have a sense of purpose.
- The right to reminisce.
- The right to know the truth.
- The right to be in denial.
- The right to be comfortable.
- The right to touch and be touched.
- The right to laughter.
- The right to cry and express anger.
- The right to explore the spiritual.
- The right to have a sense of family. (pp. xviii)

In the fullest sense, these rights are useful in recognizing what a dying person requires when he/she experiences anticipatory grief. The dying person looks to his/her family caregiver as well as to professional caregivers to acknowledge these rights and to fulfill them (Smith, 1997). Van Bommel (1989) recognized as well that the difficulties for the dying person include the inability to articulate what his/her needs are when some of them seem socially unacceptable at the time, because he/she is dying. However, the dying person's response to anticipatory grief will be within his/her characteristic range of behaviour (e.g. direct and take charge, quiet and following directions; Lamers, 2000; Rando, 2000; Smith, 1997; van Bommel, 1989).

A dying person will respond to the stress of dying with various coping mechanisms. In the past, these methods of coping were considered "defense mechanisms" and carried a negative connotation (Rando, 1984). However, Rando (1984) prefers to acknowledge these responses more positively, recognizing that for most people it is their first experience with dying and it is their attempt to manage it. Some coping mechanisms are regression, giving up, repression, denial, rationalization, and intellectualization, among others (Rando, 1984). The extent to which a dying person maintains a coping mechanism determines if it is a suitable or maladaptive response to dying. These methods of coping affect the process of anticipatory grief and can be facilitated by family and professional caregivers (Lamers, 2000; Rando, 1984; Rando, 2000; Rolland, 1991; Smith, 1997; van Bommel, 1989; Walker, Pomeroy, McNeil, & Michaellin, 1994).



## Anticipatory Grief in the Family

How a family responds to and develops through the experience of a loved one's terminal illness and death will have long ranging implications in the family. Their response creates an emotional shock wave which can affect the whole family for generations to come (Bowen, 1991). Indeed, a family's response to the diagnosis of a terminal illness in the family is a reflection on how illness and death are received within their family system (Bowen, 1991; Gilliland & Fleming, 1998; Paul & Grosser, 1991; Walsh & McGoldrick, 1991). Social work intervention is promoted as a means to affirm the experience of anticipatory grief, clarify the tasks to be addressed during this time and offer supportive intervention to manage the process of grieving (Bowen, 1991).

“The anticipation of loss in physical illness can be as challenging and painful for families as the actual death of a family member” (Rolland, 1991, p.13). The loss can be considered a shared life cycle experience when both the dying person and his/her family acknowledge the finality of death and the continuity of life. The process of accepting this time in the cycle of life is the most difficult task a family must confront (Walsh & McGoldrick, 1991).

There are complex emotions observed in families of people with chronic illnesses who are experiencing losses before someone's death (Walker et al., 1994). During these periods, families can exhibit hypervigilance and be overprotective of their loved one (Rolland, 1991; van Bommel, 1989). These emotions also have a systemic influence in the family during this time affecting family development,

realignment of family structures and role reorganization in an effort to regain homeostatic balance (Rando, 2000; Walsh & McGoldrick, 1991).

Wilson and Daley (1999) recognized the importance of family caregivers receiving support during the dying process to assist them with their anticipatory grief. Based on a dearth of information in the literature that related to family caregivers' needs, Wilson and Daley studied families of terminally ill people. This study showed that family caregivers benefited from caring behaviours of staff, participation in the dying process, and provision of spiritual care.

The conventional act of grieving in a family system operates within the family narrative. The family approaches and reacts to the death in a circular process (Walsh & McGoldrick, 1988). The transgenerational effects of previous deaths and losses have a great influence on the family's current situation (Kinsella, Cooper, Picton, & Murtagh, 2000; Walsh & McGoldrick, 1991). If the experience with disease and death in the past history of the family includes memories of people coming together to help one another and coping, the current grieving person will have role models as references in their anticipatory grief. However, if the experience of illness and death in the family has been an overwhelming experience, there can be a response that is not favourable in their coping with the current situation. Indeed recognizable ripple effects occur throughout families when they are experiencing grief such as children acting out at school, adults committing adultery and increased medical attention in the grieving family (Paul & Grosser, 1991; Walsh & McGoldrick, 1991). These factors contribute to the affirmation or to

the challenge of rebuilding a life in bereavement (Kutscher, 1973; Paul & Grosser, 1991; Rolland, 1991).

Families begin to make their own adjustments in anticipatory grief based on their beliefs of the illness trajectory (Rolland, 1991; Walker et al., 1994). At initial diagnosis, the news passes through the family filters of history, cultural background and spirituality (Rando, 2000; Rolland, 1991; Walsh & McGoldrick, 1991). Based on the fullness of their collective life experience, families will begin to respond to the immediate situation with their loved one. Rando (1984) purports that family caregivers initially vacillate between acceptance and denial of the news of a terminal illness, and that family members adjust to the diagnosis at individual rates. She also indicated that the family's ability to cope was in part due to a pattern of open communication within the family. An "open relationship system" is described by Bowen (1991) as being "one in which an individual is free to communicate a high percentage of inner thoughts, feeling, and fantasies to another who can reciprocate" (p. 80). The reciprocal situation is true as well; those families with poor communication and rigid roles also have difficulty in adjusting to any crisis (Rando, 1984). The relationship system has an "automatic emotional reflex to protect self from the anxiety in the other person" (Bowen, 1991, p. 80). Other investigators have further supported this position regarding family dynamics and their response to the news of terminal illness (Kinsella et al.; Lamers, 2000; Rolland, 1991; Walker et al., 1994; Weuve, Boult & Morishita, 2000).

When the family is required to be supportive of the loved one with a terminal illness, complexities of anticipatory grief emerge. In addition to their own feelings of guilt, helplessness, and difficulties coping with the pending loss, family caregivers are witnesses to their loved one's grieving process (Walker et al., 1994). Indeed they perceive their loved one's pain (physical, emotional and spiritual) and, stress in the final stages of living (Gilliland & Fleming, 1998; Rando, 1986; Rolland, 1991; Walker et al., 1994). Some of the guilt the family feels is related to their continued health, imperfect relationship with the dying person, and, resentment of the focus of time and resources on the individual (Kutscher, 1973; Rando, 1984). Their sense of helplessness is rooted in their inability to cure their loved one, take the pain away or change the effects of the illness (Gilliland & Fleming, 1998; Kübler-Ross, 1973; Rando, 2000). It often angers family and friends that they can't bring enough relief to their loved one. As well, they are caught in the need to balance the paradoxical tasks of "letting go" of a terminally ill person while still caring for them (Gilliland & Fleming, 1998). This feeling of helplessness is often rooted in the frustration of not being able to inhibit the disease process and to prevent death from occurring. In this way the adjustment to someone's terminal illness necessitates the anticipatory grief process to be recognized, by professional caregivers, as a complicated experience for the family caregiver which continuously changes throughout the journey of loving someone with a terminal illness until their death.

## Palliative Care Philosophy

The root of understanding palliative care begins with knowing that the word palliative is derived from the Latin word palliare which means “to cloak or cover” (Ferris & Cummings, 1995). In the 1960’s and 1970’s, Dame Cicely Saunders defined the concept of hospice care, as it related to cancer care, as the movement of intervention from cure to care (Ferris & Cummings, 1995). As the evolution of palliative care progressed into the 1980’s a more formal definition was published by The Palliative Care Foundation of Toronto, Ontario:

Palliative care is active compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms - physical and emotional- is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope. (Ferris & Cummings, 1995, p. 10)

As the palliative care movement continued to develop, the definition was adjusted and became more focused, defining primary and secondary goals as being:

active compassionate care...improving the quality of life for the dying...delivered by an inter-disciplinary team that provides sensitive and skilled care to meet the physical, psycho-social and spiritual needs of both the patient and the family. The philosophy and principles of palliative care may apply to the patient populations other than the dying and the palliative care program may have a secondary role of addressing the needs of these groups. (Ferris & Cummings, 1995, p. 10)

In 1990, the World Health Organization (WHO) suggested the definition for palliative as being:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment. Palliative care:

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and the spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement. (Ferris & Cummings, 1995, p. 11)

This definition for palliative care was further augmented, in 1995, by the Canadian Palliative Care Association (CPCA):

Palliative care, as a philosophy, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical,

psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices.

Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Palliative care is planned and delivered through the collaborative efforts of an inter-disciplinary team including the individual, family caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.

While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized palliative care program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing. (Ferris & Cummings, 1995, p.12)

The combination of these definitions of palliative care recognizes the movement from an individualized focus to a fuller focus on providing care to the individual, his/her family caregivers and professional health care providers. It recognizes the breadth of palliative care and offers support for all people involved in the care of someone in the final stages of life.

## Family Caregivers

Caregivers are people who provide informal, unpaid assistance to family and friends who have health or functional needs (Weuve et al., 2000). They are known to provide assistance in many areas: with activities of daily living (e.g. personal grooming, hygiene or, feeding), functional assistance (e.g. cooking, cleaning, shopping), emotional and financial support, as well as serving as case managers in interactions with physicians and the professional caregivers (Clair & Fitzpatrick, 1995; Lawton, Moss, Hoffman, & Perkinson, 2000; Weuve et al., 2000; Yee & Schulz, 2000). The term “family caregiver” will be used to reflect people who are biologically connected to the dying person as well as the people who are intimately connected and significant in that person’s life and not family (Rando, 2000).

The role of the family caregiver is increasing in our society parallel to the growth of the older adult population (Hills, 1998; Weuve et al., 2000). When the dying person and the family caregiver plan to go through the final stage at home it creates opportunities and challenges. Kinsella et al. (2000) state that:

home-based [palliative] care typically affords care recipients greater emotional and physical comfort and, therefore, enhanced quality of life during the terminal phase...Caregivers also report a preference for home-based palliative care because the circumstances of death are generally more intimate, peaceful, and less distressing at home. (p. 46)



However these authors and others confirm that home-based caregivers are at personal risk of developing various physical and psychological results (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Nijboer et al., 2000; Weuve et al., 2000; Yee & Schulz, 2000). Caregiver psychiatric morbidity has increasingly been studied, compared to non-caregivers, to determine the effects of caregiving on levels of anxiety, depression, physical illness, and family role strain (Yee & Schulz, 2000). The difficulty in thoroughly assessing caregiver burden is due to the absence of a baseline assessment of a family prior to their becoming involved in caregiving (Guberman, Maheu & Maillé, 1992; Miller & Cafasso, 1992; Rankin, Haut, & Keefover, 1992; Walker et al., 1994).

Due to the desire to manage the care of ill people in the community, the role of caregiver is one ascribed and not necessarily chosen (Hills, 1998). A typical caregiver is a woman working in the community, who provides care for someone in addition to her other familial responsibilities (Guberman et al., 1992; Hills, 1998; Miller & Cafasso, 1992; Walsh & McGoldrick, 1991; Yee & Schulz, 2000). Professional health care providers do not always take the characteristics and aptitude of the family caregiver into account or their former relationship with the person dying. Yet, from the onset the family caregiver has the potential of being the "hidden patient" (Hills, 1998; Kristjanson et al., 1996).

The caregiver's prior relationship to the dying person has an impact on the style of caregiving as well as his/her ability to accept the additional responsibilities (Clair & Fitzpatrick, 1995; Pomeroy & Rubin, 1995; Roach & Nieto, 1997; Walsh &

McGoldrick, 1991). It will shape their perception of the role of caregiver as one of burden or devotion. The prior relationship will also affect the amount of stress experienced and how it is defined by the family caregiver. Also, whether the caregiver is a spouse, adult child or friend, man or woman will influence his/her role and perception of caregiver tasks (Clair & Fitzpatrick, 1995; McGoldrick & Walsh, 1991; Pomeroy & Rubin, 1995; Yee & Schulz, 2000). Consequently these aspects of the prior relationship need to be assessed to determine the professional caregiver's intervention plan (Hills, 1998; Ponder & Pomeroy, 1996).

Caregiving demands have an impact on the individual physically, emotionally, financially, and spiritually (Rando, 2000; Rolland, 1991). The complete impact of the effort of caring for a dying loved one creates an enormous burden when it remains unrecognized, developing into resentment, guilt and shame for thoughts of wanting relief from their efforts (Clair & Fitzpatrick, 1995; Kinsella et al., 2000).

### Caregiving: Burden & Growth

The caregiving experience offers a mixture of outcomes. Some of them are negative and considered a burden, others are neutral or positive and considered a benefit (Kinsella, Cooper, Picton, & Murtagh, 2000; Weuve et al., 2000). Studies have shown that there are physical, psychological, social and economic ramifications to being a caregiver over varying lengths of time and conditions (Kinsella et al., 2000; Nijboer, Triemstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000;

Lawton et al., 2000; Weuve et al., 2000; Yee & Schulz, 2000). The conditions influencing the experience of caregiving determine whether it is a burden or a positive experience. These conditions include gender, age, relationship with care recipient, length of time as a caregiver, physical environment for caregiving, stage of illness and prospective trajectory (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Nijboer et al., 2000; Lawton et al., 2000; Weuve et al., 2000; Yee & Schulz, 2000).

Coping with the terminal illness of a loved one requires an awareness of the complexity of the process (Kinsella et al., 2000; Ponder & Pomeroy, 1996; Rando, 1986; Roach & Nieto, 1997; Rolland, 1991; Walker, Pomeroy, McNeil & Michaelin, 1994). In previous hospital based studies, the family needs assessments were confined to the area of communication with professional health care providers about the disease, prognosis, and level of care given to provide comfort to the loved one (Wilson & Daley, 1999). However, current studies confirm that the needs of families are more complex (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Ponder & Pomeroy, 1996; Rando, 1986; Roach & Nieto, 1997; Rolland, 1991; Walker et al., 1994). The family caregiver needs include recognition of their emotional responses, spiritual distress, psychological, physiological and social factors as well as personal death awareness, impact on the family as a whole and financial strain (Gilliland & Fleming, 1998; Rando, 1986; Walker et al., 1994; Walsh & McGoldrick, 1991; Wilson & Daley, 1999).

These needs are exacerbated by the changes in independence, physical, emotional, and social abilities of the care recipient. As the terminally ill person's

condition destabilizes, the family caregiver's general mental and physical health is affected and reflects the very stressful nature of caregiving (Lawton et al., 2000; Nijboer et al., 2000; Pomeroy & Rubin, 1995).

Weuve et al. (2000) go further to define caregiver burden in objective and subjective terms. The tangible outcomes of caregiving, which disrupt the caregiver's lives, such as demands on their time, income and efforts of caregiving are the objective burdens. Subjective burden describes the caregiver's feelings about their actions as a caregiver (Weuve et al., 2000).

Although there are significant challenges within the role of family caregiver, the positive aspects of it must be recognized. The period of time in which a family responds to a loved one's terminal illness creates a window of opportunity to adjust the family's level of functioning and increase the probability of there being a therapeutic anticipatory grieving period (Rando, 2000). The caregiver's role provides an opportunity of adjustment to the imminent loss, to the new life ahead all the while being in the living-dying trajectory with a loved one (Rando, 2000; Walsh & McGoldrick, 1991). It is an opportunity to reflect on their previous relationship with their loved one and prepare for a life without them. Caregivers have an opportunity to learn from their loved one how to manage the household, to involve the support network of family and friends as well as professional caregivers (Rando, 1984). Being a caregiver is an opportunity to confirm family values, validate the relationship with the person dying, and rehearse new social roles without their loved

one (e.g. going to social function without their partner; Rando, 1984; Rando, 2000; Rolland, 1991; Walker et al., 1994).

The period of being a caregiver for someone with a terminal illness also gives the caregiver an opportunity to learn or improve on his/her communication skills (Byock, 1997; Rando, 2000; Walker et al., 1994). It allows an opportunity for a catharsis of emotion, to relieve anxiety, sort out past issues and resolve current issues. Indeed the act of actually physically caring for a loved one can transcend words, giving the dying person a sense of wellbeing and security (Buchanan, 1984). Through these actions the caregiver gains a sense of control and mastery which boosts their confidence in their ability to cope with the dying of their loved one (Buchanan, 1984; Rando, 2000; Rolland, 1991; Walsh & McGoldrick, 1991).

The act of caregiving provides the family an opportunity to adapt to their future loss, to put it into perspective within the cycle of life and to strengthen their family network in preparation for their period of bereavement (Bowen, 1991; Buchanan, 1984; Rando, 2000; Rolland, 1991; Walsh & McGoldrick, 1991). Byock (1997) maintains that this period of time is an opportunity for caregivers to say, “I love you, thank you, I forgive you, forgive me, and, good-bye” to their loved one.

### Caregiving Factors

Age. There are many factors affecting the caregiver and whether there is a satisfactory outcome of his/her being a caregiver (Kinsella et al., 2000; Rando, 2000; Walsh & McGoldrick, 1991). The age of the family caregiver is one factor to

consider. Kinsella et al. study (2000) determined the higher the caregiver's age the more susceptible and vulnerable he/she may be due to his/her own health issues. However, the older the caregiver's age the more accepting he/she was of the role of being a caregiver to his/her loved one, having had previous experiences as a caregiver or more role models to refer (Hegge & Fischer, 2000; Kinsella et al., 2000; Moos, 1995). The younger person experiences more challenges as he/she assumes the role of being a caregiver. Younger caregivers report more of a burden due to role strain; such as being an employee and a parent of young children (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Miller & Cafasso, 1992; Nijboer et al., 2000; Rolland, 1991). This "off-time" terminal illness, as perceived by the family at any age and stage of family life, may place the family at higher risk for dysfunctional consequences as a result of their lack of psycho-social preparation for the loss (Nijboer et al., 2000; Rolland, 1991; Walsh & McGoldrick, 1991).

Gender. Walsh & McGoldrick (1991) identified gender as an important issue for therapists to address. Traditionally women are the primary caregivers for their families and friends when emotional or physical ailments arise. They typically provide their loved one with more day to day, hands-on type of caregiving such as cooking, cleaning and personal care (Guberman et al., 1992; Kinsella et al., 2000; Miller & Cafasso, 1992; Yee & Schulz, 2000). These tasks are time consuming and demanding on a woman's time and energy. Women caregivers are more likely than male caregivers to be distracted at work, use sick leave to respond to their loved one's needs or actually have a reduced work commitment (even withdraw from the

labour market) as a result of their being a primary caregiver (Nijboer et al., 2000; Yee & Schulz, 2000).

This level of responsibility creates high levels of caregiver burden in women. They are more inclined to report lower life satisfaction, depression, anxiety, and a reduced sense of mastery than non-caregiving women (Nijboer et al., 2000; Yee & Schulz, 2000). The strain of being a primary caregiver is felt by the woman within her relationship with the person with a terminal illness, the family or marital relationship (Clair & Fitzpatrick, 1995; Lawton et al., 2000; Medigovich et al., 1999; Ponder & Pomeroy, 1996; Walsh & McGoldrick, 1991; Yee & Schulz, 2000). This appraisal of caregiver burden from women can also be attributed to their ability to express and identify their feelings more than men (Kinsella et al., 2000; Miller & Cafasso, 1992; Nijboer et al., 2000).

Limiting the role of caregiving to women prevents men from actualizing their human potential. It negates their emotional expressiveness and denies men's abilities to contribute to relieving the family crisis (Walsh & McGoldrick, 1991). Such limitations block the men from developing their social-emotional potential, from sharing the experience of being a caregiver, and limits the flexibility of their roles within their family life (Kinsella et al., 2000; Nijboer et al., 2000; Walsh & McGoldrick, 1991). Golden and Miller (1998) distinguish the different ways in which men respond to loss and grief as such acknowledging the differences and similarities between the style of grieving men and women. Due to their lack of experience as nurturers, men offer their involvement with caregiving in a secondary

caregiver role; offering functional/practical intermittent support to the loved one with a terminal illness (Kinsella et al., 2000; Walsh & McGoldrick, 1991; Miller & Cafasso, 1992; Yee & Schulz, 2000).

As caregivers, men are at a higher risk for caregiver strain if they abide by the traditional male role of hiding their emotions (Kinsella et al., 2000). Society's denial of male vulnerability and dependency needs contribute to their lack of emotional expression causing their needs to be more hidden. Their concerns also tend to be focused on role changes within the family, changes in the family routine, and financial issues (Kinsella et al., 2000; Miller & Cafasso, 1992; Walsh & McGoldrick, 1991). A review of thirty empirical research studies relating to gender differences in caregivers identified that men are more likely than women to have caregiving tasks of an intermittent quality, such as transportation, home maintenance and financial care management (Yee & Schulz, 2000). Male caregivers, whether spouses or adult children, ask for or are offered professional caregiving services more frequently than women. As a result men expressed less caregiver burden than women as measured by their reported level of depression, anxiety and life satisfaction in part due to the minimal interruption to their work and family, which continue to provide validation (Kissane et al., 2000; Yee & Schulz, 2000). However, emotionally, male caregivers have a higher rate of complicated grief reaction than women due to their being unprepared for the experience of caring for a loved one until his/her death (Kinsella et al., 2000; Walsh & McGoldrick, 1991).



Many researchers have recognized the imbalance between women and men and their caregiving responsibilities as they contribute to marital and family strain (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Lawton et al., 2000; Medigovich et al., 1999; Miller & Cafasso, 1992; Nijboer et al., 2000; Ponder & Pomeroy, 1996; Walsh & McGoldrick, 1991). Miller & Cafasso (1992) determined the gender imbalance was in part due to the older adult's expectations for a woman to be the caregiver more than a man in their family. The persistence of gender stereotypes in society will continue to influence who will be a family caregiver and how supported he/she will be by the services of professional caregivers. Social workers need to intervene in a sensitive manner to relieve caregiver burden and provide choices which the family can accept within their definition of acceptable roles for men and women in their family (Buchanan, 1984). When the family caregiver is supported in his/her efforts to provide care for the loved one, it affects the loved one's health and perception of professional caregiver's services to be satisfactory (Medigovich et al., 1999). By caring for the family caregivers, the professional caregiver recognizes the whole family as having needs, not only the family member with the terminal illness.

Relationship. The issue of the caregiver's relationship with the person who is dying has received widespread consideration. It is understood as an important factor in the experience of caregiver burden (Baider et al., 1998; Clair & Fitzpatrick, 1995; Guberman et al., 1992; Gilliland & Fleming, 1998; Kinsella et al., 2000; Miller & Cafasso, 1992; Rando, 1984; Rankin, Haut & Keefover, 1992; Toseland, Labrecque, Goebel, & Whitney, 1992; Walsh & McGoldrick, 1991).

Whether the caregiver is a spouse, son or daughter, brother or sister, mother or father, their relationship brings to the task of care giving different dimensions. It has been determined that spouses who are caregivers report a higher level of caregiver burden than family caregivers in different relationships. Due to the nature of his/her relationship, the greater time commitment and increased isolation, family caregivers who are spouses are at a higher risk than other family caregivers for greater caregiver strain and adverse personal health results (Baider et al., 1998; Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Toseland et al., 1992).

Other family caregiver's level of burden is affected by their relationship with the dying person. The significance of the dying person's role in the family has an impact on the caregiver's burden. Whether the death is considered timely or premature, how long a person has been ill, the quality of the relationship, and, how it fits within the context of the family system, will determine the impact on the family caregivers' level of burden (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Moos, 1995; Rando, 1984; Rolland, 1991). The complexity of any family needs to be recognized and responded to by the whole professional caregiver team in an effort to fully support the dying person in their care (Gilliland & Fleming, 1998; Hill, 1998; Kinsella et al., 2000; Kissane et al., 1998; Kristjanson et al., 1996; Wilson & Daley, 1999).

### Professional Response

Intervention is highly recommended for the families as a whole to ensure the wellbeing of all caregivers (Bowen, 1991; Hills, 1998; Kinsella et al.; Kissane et al.,

1998; Rando, 1984; Rolland, 1991; Walsh & McGoldrick, 1991). A family assessment is acknowledged as being beneficial to determine the caregiver's perspective on the role and responsibilities ascribed. It is helpful to determine if the prior relationship can sustain the impact of the caregiver role (Hill, 1998; Pomeroy & Rubin, 1995) as well as the family system's experience with grief and loss (Bowen, 1991; Gilliland & Fleming, 1998; Kissane et al., 1998; Rando, 2000; Walsh & McGoldrick, 1991). Also, social work intervention can lessen the gender-related imbalance and differences to caregiving and facilitate the individual expression of anticipatory grief (Walsh & McGoldrick, 1991). It is necessary for the social worker to recognize the interconnectedness of the symptoms of a grieving family and not consider them as separate events. Bowen (1991) referred to the fullness of emotional and physical symptoms as the "shock waves" in families reacting to someone's dying (p. 85). If there is an appreciation of possible shock waves in the family system due to someone's terminal illness, a social worker can intervene in a preventative manner (Bowen, 1991; Kissane et al., 1998; Rolland, 1991; Walsh & McGoldrick, 1991).

The family caregiver's importance is not limited solely to the physical care of the individual with the terminal illness but it includes "the interpretation and imparting" of intimate knowledge of the loved one's symptom experiences (Lobchuk & Stymeist, 1999). This vital aspect of being a caregiver underlines the importance of supporting the family throughout the process of a loved one's terminal illness. Family caregivers are effectively the bridges between the health care receiver and

the health care provider (Kristjanson et al., 1996; Rando, 1984; Roach & Nieto, 1997).

The family caregiver can interpret the symptom experiences and the cultural construct of illness to the health care provider. Indeed, he/she can explain and give meaning to the subtleties of a family's distress signals (Lobchuk & Stymeist, 1999). By consulting the family caregiver, the multidisciplinary health care team blends all of the necessary components for providing exceptional care for the terminally ill person (Kissane et al., 1998; Kristjanson et al., 1996; Kutscher, 1973; Rando, 1984; Roach & Nieto, 1997). With this perspective, consideration for the emotional health and support of a family caregiver is a necessary intervention.

Preliminary research has indicated a close relationship between the quality of life experienced by the person who is terminally ill and the family members whose wellbeing is considered important by the health care professional (Kinsella et al., 2000; Kissane et al., 1998; Kristjanson et al., 1996). The complexity of intervention for a person with terminal illness and his/her significant others cannot be underscored enough. Families who do not function well or are not well supported, during this phase of a person's illness are the ones considered most at risk for the bereavement period. As a further result, they will require considerable intervention in their bereavement (Kinsella et al., 2000; Kristjanson et al., 1996; Kutscher, 1973; Nijboer et al., 2000; Walker & Pomeroy, 1996; Weuve, Boult & Morishita, 2000).

If a family does not receive adequate social work intervention prior to a loved ones' death, there are significant risks. These risks include the full range of

poor family functioning, from difficulty sustaining emotional bonds with loved ones (Zilberfein, 1999) to psychiatric morbidity in the bereavement period (Medigovich, 1999; Nijboer et al., 2000; Paul & Grosser, 1991). Other researchers noted that the high risk factors which caused bereavement to be an arduous task were present in the families prior to the death of a loved one (Ponder & Pomeroy, 1996; Walsh & McGoldrick, 1991; Zilberfein, 1999). Consequently, the professional assessment and intervention with families of people with a terminal illness is critical. It benefits the person with a terminal illness, facilitates the palliative care process, and prevents a further strain on the family and medical system (Bowen, 1991; Kissane et al., 1998; Kristjanson et al., 1996; Nijboer et al., 2000; Ponder & Pomeroy, 1996; Rando, 1984; Rolland, 1991).

### Social Work Approaches

#### Group Intervention

Bringing people together with common life challenges diminishes the sense of isolation, and makes connections between people responding to similar life situations (Benioff & Vinogradov, 1993; Cherubin, Flynn, & Morgan, 1998; Daniolos, 1994; Heller & Roccoforte, 1997; Klien, 1993; McCallum, Piper, & Morin, 1993; Toseland & Rivas, 1998). This common experience provides an “installation of hope” and supportive feedback from peers, in this case other family caregivers, with the benefit of a social worker’s involvement (Benioff & Vinogradov, 1993; Drum & Knott, 1977; Pomeroy & Rubin, 1995; Toseland & Rivas, 1998). It has been

described as “an effective and important psychosocial intervention for patients with cancer” (Benioff & Vinogradov, 1993, p. 477). Group therapy has been determined as beneficial for family caregivers of people with AIDS, Alzheimer’s disease as well as people in bereavement (Heller & Roccoforte, 1997; McCallum et al., 1993; Pomeroy & Rubin, 1995). As a result it points to the possible benefits for family caregivers of people with a terminal illness.

Benefits of group intervention. There are four supportive factors in group therapy that provide group members with an immediate sense of “belongingness” (MacKenzie, 1990). These factors are basic installation of hope, acceptance, universality, and, altruism (MacKenzie, 1990). Together these curative factors nurture the group member’s sense of mastery and self-esteem, which benefits family caregivers who are deficient in these areas due to caregiver burden (Benioff & Vinogradov, 1993; Crandles & Sussman, 1992; Drum & Knott, 1977; McCallum et al.; Pomeroy & Rubin, 1995; Walker & Pomeroy, 1996).

Groups also provide the opportunity to develop interpersonal skills within a microcosm that participants can use in their family situations. Within groups people have an opportunity to practice self-disclosure, the act of placing issues “on the table” and have interaction with other group members (MacKenzie, 1990). Self-disclosure is a necessary skill to practice when someone is experiencing anticipatory grief and needs to respond to their loved one in the “here and now”(Crandles & Sussman, 1992; Hegge & Fischer, 2000; Klein, 1993).

A possible catharsis is another benefit of a group experience. Catharsis refers to expressing deeply held feelings. The release of these emotions reduces the pent-up pressure of unexpressed grief and is a natural process. The combination of self-disclosure and catharsis creates a therapeutic opening for consideration of changes at both a cognitive and emotional level (MacKenzie, 1990).

Interaction within the group promotes the opportunity for altruism. Each family caregiver enters a group with his/her experience of caregiving and will leave with a new reflection on it based on interaction with other group members. The group cohesion creates an opportunity for the participants to model different behaviour, educate each other about ways to cope with their level of burden and offer guidance to one another (Cherubin et al., 1998; Crandles & Sussman, 1992; Klein, 1993; MacKenzie, 1990; Toseland & Rivas, 1998; Walker & Pomeroy, 1996).

Limitations Associated with Group Intervention. A primary limitation associated with social work group intervention often relates to leadership. Rutan and Stone (2001) refer to group intervention as an “art more than a science” and they recognize that no two social workers will provide intervention alike due to their unique human nature. It was also noted that within the therapeutic process the group facilitator receives a vast amount of information from each group participant that requires synthesis and a therapeutic response. Consequently a social worker requires considerable experience and training to competently lead a group (Toseland & Rivas, 1998).

Adequate group leadership skills are required to manage the group and individual goal achievement. These skills are used to attend to beginning and ending the sessions on time, nurturing each participant's involvement, facilitating the communication and therapeutically guiding group interaction. Without the necessary skills, a facilitator inhibits the group process, curative factors, and individual development thus limiting the therapeutic outcome (Toseland & Rivas, 1998). These limitations block the formation of therapeutic alliances, individual emotional development, and effective conflict resolution. Concerns about group leadership can be managed or resolved with proper supervision and adequate training.

The next obstacle to successful group interaction is membership. The importance of preliminary group participant screening is a process that is sometimes minimized. It is not seen as a fundamental process to building dynamic therapeutic groups. Often the need for adequate numbers of group members supercedes considerations regarding group composition. Indeed the composition of a group is an essential component to the group's success as well as how individual members are an influence on the group process (Rutan & Stone, 2001; Toseland & Rivas, 1998).

The responsibility for a group's composition is shared by the referring clinician and the group facilitator (Rutan & Stone, 2001). Consideration for mental health issues, language barriers and ability to hear are all necessary to be reviewed when determining the effect on the group as a whole and the impact on the



individual in the group process. The experience and willingness of the therapist to accept these challenges within a group process determines if someone with these limitations is included in the selection of group members. It is critical for the group facilitator to assess these conditions and balance the individual's needs with the therapeutic process of a group (Rutan & Stone, 2001; Toseland & Rivas, 1998). When these issues are attended to then the problems associated with social work group intervention are manageable and no longer thwart the therapeutic group process.

**Brief group intervention.** Brief group intervention is described as any group which lasts less than six weeks, meeting on a weekly basis for 45-90 minute sessions, having a limited therapeutic focus, and, using a variety of clinical methods of intervention. The goals of brief group therapy must fit with the group member's needs and be reachable within the time frame (Benioff & Vinogradov, 1993; Klein, 1993; Rutan & Stone, 2001).

The structure of a brief group intervention allows members to reach an identified goal within a minimum of time commitment, in this case a minor amount of time away from their loved one with a terminal illness (Drum & Knott, 1977; Kissane et al., 1998). This mode of intervention accommodates family caregivers with a limited ability to make a long term time commitment due to their loved one's terminal illness (Heller & Roccoforte, 1997; Kissane et al., 1998).

Pomeroy & Rubin (1995) determined that their eight-week psychoeducational task-centred group significantly reduced the caregivers' burden

within the group time frame, as compared to those in the control group. In another study of supportive groups for family caregivers of people with a mental illness, Heller & Roccoforte (1997) determined that groups appeal to a cross-section of people who have a common experience of being caregivers. Even those caring for a loved one requiring significant day to day support, attended, and benefited from the group experience. In Walker & Pomeroy's study (1996), psychoeducational groups for caregivers were determined to be beneficial in many ways. Group members became supportive of each other between groups, attended funerals and continued to be involved in each other's bereavement. Eventually some of these group participants had a positive impact on their community through public speaking in schools. Social work intervention in groups creates opportunities for caregivers to speak about and be supported in their experience of anticipatory grief through the different phases of the terminal illness.

Researchers have shown that a reduction in the psychosocial morbidity in the family members occurs when a family is offered grief therapy during palliative care and bereavement (Kissane et al.1998; Lamers, 2000). These different studies support the belief that family caregivers will take the time to participate in groups and benefit from them even when their loved one requires significant care.

Co-Leadership. The practice of offering therapeutic groups with two leaders has been frequently debated (Douglas, 1976; MacKenzie, 1990; Nichols & Schwartz, 1998; Toseland & Rivas, 1998). Certain therapeutic approaches, such as strategic,

Milan, narrative and experiential, regularly use co-leaders to ensure balance and objectivity in the facilitator (Nichols & Schwartz, 1998).

Advantages & issues of co-leadership. A list of the most frequently noted benefits of co-leadership was found in Toseland & Rivas' book "Group Work Practice" (1998). They listed the following benefits:

Leaders have a source of support.

Leaders have a source of feedback and an opportunity for professional development.

A leader's objectivity is increased through alternative frames of references.

Inexperienced leaders can receive training.

Group members are provided with models for appropriate communication, interaction, and resolution of disputes.

Leaders have assistance during therapeutic interventions, particularly during role-plays, simulations, and program activities.

Leaders have help setting limits and structuring the group experience.

(p. 122)

Nichols & Schwartz (1998) noted that groups with highly emotional contents are better supported by having two therapists to respond to the interactions. Given the number of interactions within the group, having co-leadership offers the opportunity to be more accurate in defining group process and assessments of the members (MacKenzie, 1990; Toseland & Rivas, 1998). Having

facilitators of each gender also invites the opportunity to model or explore gender roles, manner of communication, parenting or as a couple (Nichols & Schwartz, 1998; Toseland & Rivas, 1998).

The concerns about co-leadership focus on issues related to balance of skills, power struggles, conflict between intervention approaches and added time to debrief or prepare for each session (MacKenzie, 1990; Nichols & Schwartz, 1998; Toseland & Rivas, 1998). MacKenzie (1990) continued in his discussion about the downside of co-leadership, when he included the concept of limited or passive responses of one or the other social worker in the group. In this regard, his concern was about one leader abdicating his/her level of involvement due to his/her perception of the process and goal of the other facilitator. The confusion between the leaders can also contribute to the group members' levels of anxiety and sense of security (Nichols & Schwartz, 1998).

MacKenzie (1990) recommends that the experience of co-leadership be closely supervised after having carefully chosen suitably matched leaders. Toseland & Rivas (1998) support this notion and suggest that more research is required about the effectiveness of groups with co-leadership. Meanwhile they recommend frequent meetings to plan the groups and discuss group process issues that arise. The benefits and detractions of co-leadership are further influenced by financial constraints of social services and managed care which has an impact on the frequency of supervision and length of intervention (Nichols & Schwartz, 1998).

## Narrative Therapy

This approach is nonhierarchical which looks to the meanings of family stories, how life stories are expressed. Traditionally, narrative is that structure which has been considered what we use to make sense of things (Kelly, 1995).

Narrative therapy is a strength based approach which facilitates the client's understanding of adverse life events within the context of his/her ongoing family life story (Eron & Lund, 1996; Kelly, 1995). It is a process of discovering the client's perspective of his/her current situation based within his/her family's stories.

The narrative social worker does not impose changes nor set goals for the client but introduces questions through which the individual may reflect on their current problem saturated story and seek alternative meanings in a broader context (Kelly, 1995; Moules & Streitberger, 1997; White & Epston, 1990). The social work intervention in narrative therapy works to deconstruct the difference between the reality of the situation and the individual's internalized stories and to find the meaning of these stories. The therapeutic process creates an opportunity for a person to "re-author" his/her own life according to the alternative and preferred stories about him/herself (Kelly, 1995). The narrative therapist works with the client to find the exceptions to his/her story and then develops it to reveal his/her capacity to manage within his/her current life situation. Some of the exceptions are found in the stories the individual retells about the past and there is a conflict with how s/he is today, which can affect how s/he responds to his/her present situation.

The act of telling their story gives caregivers an opportunity to validate their struggles. It is a means through which their anticipatory grief can be expressed within the context of their life (Eron & Lund, 1996; Holland & Kilpatrick, 1993; White & Epston, 1990; Wingard, 1998). Gradually the problems are deconstructed into challenges which the caregiver has the strength to manage and to strive for goals to once again achieve some sense of balance within their life situation (Kelly, 1995; White & Epston, 1990).

In the crisis of loving someone with a terminal diagnosis, choices are not always readily recognized. "Narrative therapy is a process for people to experience choices" (Cheung, 1998, p. 7). By presenting options to the caregiver, the social worker opens up the space for different choices to be made. The process of collaboration, between the social worker and the group members as well as between the group members, naturally affects group cohesion and will facilitate the process in the brief time period. The benefits will also affect the dying loved one, the palliative care process and the family caregiver's bereavement (Kissane et al, 1998).

Narrative therapy in a group setting is a unique approach with the facilitator in the position of being neutral. Through questioning from the position of "not knowing", the practitioner conveys the basic trust in the client's potential to solve his/her own challenges and find his/her own solutions (Cheung, 1998; White & Epston, 1990). The exposure to sharing stories, knowledge and strengths can be a very empowering experience (Cherubin et al., 1998; Kelly, 1995; Nichols & Schwartz, 1998). In true narrative form, this group could become so empowered

that they will effect change in their families as well as within their community (Cherubin et al., 1998; Nichols & Schwartz, 1998; White & Epston, 1990; Wingard, 1998). Within this framework, the individual and family resiliency is discovered, acknowledged and strengthened causing a reduction in their possible vulnerability to future challenges (Cheung, 1998; Kelly, 1995; Walsh, 1998).

### Experiential Therapy

The narrative therapy approach is considered by critics to be too “reductionistic” and cognitive in its approach (Nichols & Schwartz, 1998).

Combining the narrative approach with the experiential approach recognizes the whole emotional experience of family caregivers (Bohart & Tallman, 1998; Connell, Mitten, & Whitaker, 1993; Nichols & Schwartz, 1998). Experiential approaches promote emotional expression to allow the individual’s natural abilities to be fully operational in an effort to respond to life’s challenges (McCallum et al., 1993; Nichols & Schwartz, 1998). Experiential opportunities to express feelings are provided in the eclectic form of using different activities such as role-playing, sculpting, use of symbols, imagery or an empty chair (Bohart & Tallman, 1998; Mahrer, 1998; Nichols & Schwartz, 1998).

The use of these therapeutic activities is motivated by the belief that people have the capacity to change, a natural “self-righting process” when it is has the opportunity to be activated within a proper environment (Bohart & Tallman, 1998, p. 180). The belief in an individual’s ability to be his/her own change agent is

confirmed through the provision of activities, which experientially generate new perspectives and meanings (Bohart & Tallman, 1998).

In a long-term group therapy process the culture of a group becomes apparent over time through the discovery of shared symbols, metaphors and context (Ettin, 1994). Within brief therapy groups, the use of some structure allows the therapist to focus the sessions according to the defined goals and to offer metaphors to facilitate the group process of recognizing their shared symbols. In this manner, the therapist makes optimal use of the time limitations (Dossick & Shea, 1988; Drum & Knott, 1977) and eases into the symbolic representation of the family caregivers' experience of loving someone who is dying (Connell et al., 1993; Ettin, 1994; Lobchuk & Stymeist, 1999). The use of symbols permeates language, connecting it with the world of experience, which is known through our senses (Connell et al., 1993).

Given the complex emotional state of family caregivers of a loved one with terminal illness, group development is facilitated by creating a common experience to encompass the many perceptions of their similar family situations (Ettin, 1994). The symbolic meaning and worldview of illness within each family is expressed through the group member's discussion and reaction to his/her loved one's experience of symptoms (Lobchuk, 1999). The experiential nature of the practicum group is strength-based with the belief that people are capable of being proactive and having been resilient in their lives, are able to meet the current challenges within a supportive environment (Bohart & Tallman, 1998; Walsh, 1998; White &



Epston, 1990). Together the group members will reflect on their common experiences of being caregivers of someone with a terminal illness. Through the use of experiential activities, and in discussion with other caregivers, they will also develop more choices in how to continue being caregivers in the future.

One of the challenges of the experiential approach in group work is providing a range of possible responses and methods to accomplish the activity within a characteristic manner for the group member. However, small groups do provide people the opportunity to step outside their traditional manner of behaviour and attempt to experiment with new responses (Nichols & Schwartz, 1998). Given that the experiential activity will be within a narrative approach and not a psychoanalytic approach, the freedom for the group member to review his/her behaviour and responses will be an opening through which exceptions could evolve into new behaviour (Nichols & Schwartz, 1998).

Mahrer (1998) discussed the goal of in-session changes using an experiential approach, with individuals, to become post-session changes. He proposed that the opportunity to experiment with the new behaviour with a person outside his/her family circle develops the client's confidence to take it out into the world of "extratherapy" (Mahrer, 1998). When caregivers in a psycho-educational intervention, the Minnesota Family Workshop (MFW), were assessed five months after their workshop, it was determined that their behaviour had changed and their level of caregiver burden had diminished from their pre-study level (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

Researchers and professional caregivers recognize the concept of anticipatory grief as being a critical component in a family caregiver's experience of caring for a loved one with terminal illness. A brief group social work intervention will normalize the process of anticipatory grief in family caregivers, facilitate the required psychosocial adjustments to their situation and facilitate their progress through a difficult time in their lives. Through the use of narrative therapeutic intervention the co-leaders will facilitate the family caregivers' learning about their family caregiving stories. This social work intervention includes the use of experiential activities to augment insight and develop discussion.

## Chapter Three

### Description of Practicum

A setting where group members are supported in an active learning role gives them an opportunity to gain new perspectives and meaning to their current situation. "Cancer Caregivers: Here & Now" created such an opportunity through the use of structured activities for individuals, pairs and the whole group, to discover their strengths and abilities within the empathetic environment of a therapeutic group. The individual's self-determination in therapy is quite important and the short-term group social work intervention model actively promotes his/her empowerment (Bohart & Tallman, 1998; Cowger, 1994; Eron & Lund, 1996; Klein, 1993).

The expectation was that family caregiver groups would relieve the intensity of acute symptoms related to anticipatory grief (Gilliland & Fleming, 1998; Rolland, 1991). It was expected that the additional understanding of anticipatory grief could facilitate later benefits for the bereaved with increased ability to cope with past, present and future losses associated with the death of their loved one (Bowen, 1991; Gilliland & Fleming, 1998; Paul & Grosser, 1991; Rolland, 1991). Understandably, not all of the caregivers involved with a terminally ill person could attend the groups. So it was hoped that the participating caregiver would have a positive influence on other family member's abilities to function in their distress (Bowen, 1991).

## Group Intervention

The following were the four goals for the practicum groups. Due to the short-term nature of the groups and practicum experience, it was important to present achievable goals for the intervention plan. These goals were used to evaluate the sessions and the effectiveness of the intervention.

1. To relieve, and normalize, the process of suffering for family caregivers of people with a life threatening illness, through the provision of multifamily, anticipatory grief groups.
2. To engender confidence within the family members to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.
4. To evaluate the satisfaction of group participants and their perception of the usefulness of the intervention in increasing support for family caregivers of people with a terminal illness.

These goals provided a framework for the practicum. Content for each group session was based on the literature review, consultation with former family caregivers and professional health caregivers. The time-limited nature of the groups encouraged the social workers and the participants to focus on relevant, current issues and avoid any long-standing family issues (Kissane et al., 1998). Ultimately it

evolved and was shaped by the participants' focus and the social workers assessment for a suitable response.

Co-leadership. Ms Ela Minaker BSW was approached to co-lead the groups. She had recently completed her final field placement at St. Boniface General Hospital with CancerCare Manitoba and came recommended by my advisor. We met three times prior to the first group's beginning and then every week before to prepare and after to debrief each session. Ms Minaker was given a copy of the practicum proposal and some other resources to assist her with her preparation to co-lead the groups. She was not involved in the promotion the pre-group interview process for the practicum, as determined by the practicum student.

The practicum included two five-week groups for family caregivers of people with a life threatening illness. "Cancer Caregivers: Here & Now" consisted of adults who were the spouses/partners, parents, friends, children or siblings of someone in the final stage of life. The goals of the groups were to facilitate the family caregiver's entry into anticipatory grief and to ameliorate the experience in preparation for the uncertainty of the living/dying process (Rando, 1984). The original practicum plan was to have two groups running concurrently on the same day, a late afternoon and an evening group. With the low registration for the first practicum group, there were only enough people for one groups. The afternoon time for the group, 4:00 - 5:30p.m. was chosen as the time for both the group. When it was determined that the group would be offered again in September, the same time and place was kept.

**Recruitment.** The first practicum group was promoted directly with a letter from Hospice and Palliative Care Manitoba (HPCM) and a pamphlet to potential group participants (Appendix A). The letter introduced the group, the facilitator and endorsed the practicum. The pamphlets were also distributed through CancerCare Manitoba, at St. Boniface General Hospital (SBGH) and Health Sciences Centre (HSC), Home Care Palliative Care nurses, Hope Breast Centre, Breast Health Centre, Seven Oaks General Hospital (SOGH) and several doctors. When there was a limited response the first time, it was decided to test out the use of a simpler method of advertising combined with another contact and promotion of the practicum by the student. Consequently a poster was created with the basic information included on the sheet and it was posted throughout the community or given to people directly (Appendix B). The student also made telephone contact with the professional teams and reviewed the practicum groups with them.

The second group received a larger number of referrals. It could have been due to the simpler poster being more effective in that it contained fewer details which individuals could easily assimilate. Or the response could have been related to the timing of the second group, in September, when there were more professional caregivers available to make referrals than in August for the first group. Another possible reason for the influx of referrals was the renewed contact with the referring group of professionals.

An avalanche of requests was anticipated as the initial response to the advertisements. However, the experience of a minimum response indicated that

there could be some other factors to consider. In discussions with my advisor, we wondered if one reason was the sense of a family caregiver's vulnerability precluded a referral by the professional caregiver to an unknown professional (practicum student's credibility). Or the different approaches by the various professionals involved i.e. nurses' versus social workers' styles of intervention or beliefs about group intervention, especially one that was brief and not ongoing.

Another possibility for a limited response could have been due to the family caregivers' perspective on the groups. They may have had a sense of loyalty to their primary source of professional support, or a reluctance to joining a group, or their sense of not having enough time to commit to a weekly group for themselves when their loved one was their primary concern. This sense of being overwhelmed could have also contributed to the fact that they did not notice the posters or pamphlets in the offices or hospital settings. These possible reasons, offered to the practicum student in conversation with participants and clinical referrers all underline the value of personal contact with the family caregivers and supportive recommendations from a professional caregiver.

Referrals came from HPCM, health-care providers in the community or hospital setting, or by self-referral. HPCM supported the practicum by offering their telephone number and voicemail system, occasional office and meeting space, and, administrative support in the form of secretarial services, photocopying, postage etc. Of most importance, HPCM was a source of credibility to the practicum.

The target population was adult caregivers, parents, spouses, siblings, and friends of people with a life threatening cancer diagnosis. Referrals were for people from a variety of cultures, educational backgrounds, ages, and both genders. Although the invitation to participate was open to both men and women, research has shown that the woman has the dominant role of nurturer of the family (Baider et al., 1997; Guberman et al., 1992; Kinsella et al., 2000; Lawton et al., 2000; Miller & Cafasso, 1992; Yee & Schulz, 2000). The gender imbalance was anticipated, and managed within the groups. The ability to nurture is ably done by men and recognizable differences of caregiving methods were respected (Crocker Houde, 2001). The caregivers' group was able to contribute awareness and skill development to all, regardless of their gender.

Seven people were referred to the first group and nine people for the second group. Of the sixteen people, three were men and husbands, three women were siblings, two women were daughters, one was a mother, and seven women were wives of someone with a life threatening illness. Once referrals had been received, the individuals were contacted for confirmation of their participation and to arrange an interview. The preliminary interview further informed the family caregiver about the group and provided an opportunity for the social worker to consider the person's suitability for participation.

During the interview process, suitability for group participation was assessed and the details of each individual's situation was determined. The person's ability to speak, understand English and have an adequate level of hearing were important



criteria. Information regarding the group was given as a pre-group orientation. After being interviewed, appropriate individuals were invited to participate in the group. Provision had been made to refer inappropriate individuals to another source for therapeutic intervention, but this was not required and all were deemed suitable to participate.

### Informed Consent

When the person had been accepted as a group member, a consent form was signed to show agreement and understanding of the practicum purpose and format (Appendix D). If the caregiver had been considered appropriate for the caregiver group, the group meeting times and location was discussed. Conversely, if a caregiver was not deemed suitable for the groups, a referral to another social worker at the agency of referral was offered for individual intervention (HPCM, St. Boniface General Hospital, Breast Health Centre, etc.).

### Description of Participants

Four people were referred to the group by HSC, and three people through SBGH. One person in the group heard about it from two different sources, SBGH and HPCM. Five people were interviewed prior to the group, the other two people withdrew, one due to changing her mind about joining and the other person's partner died. Another person withdrew prior to the group beginning due to the

death of her partner. Thus, the group then began with four people, three women and a man. The following is a brief description of the group members:

- Barbara was a woman in her 60's whose younger sister had a life-threatening cancer. St. Boniface CancerCare Manitoba Centre and HPCM referred her to the support group. She had no previous experience with support groups although she has had experiences within groups through church and professional associations. Her goals for the group was to learn what to say and do to help her sister.
- Susan was a woman in her 60's whose younger sister had a life-threatening cancer. HSC CancerCare Manitoba Centre referred her to the support group. She had no prior experiences with groups other than family and school. Her goals for the group was to learn more about helping her sister and how to cope better for herself.
- Mary was a woman in her 30's whose husband had a life-threatening cancer. HSC CancerCare Manitoba Centre referred her to the group. She had no prior support group experience. Her reason for coming was to not feel so alone and to help other people with what she has learned so far.
- Wayne was a man in his 60's whose wife had a life-threatening cancer. HSC CancerCare Manitoba Center referred him. He had previous experience in a support group and with community groups. His goals for coming to the support group included learning how to cope with the ups and downs of this process.

Nine people were interviewed for the second group, eight people came for the first session and four people came to every session. Four people were referred from HSC, two were from SBGH, one from HPCM, one by Home Care - Palliative Care nurse and one by word of mouth from the community. Thus, the second group then began with eight people, six women and two men. The following is a brief description of the group members:

- Michael was a man in his 60's whose wife of many years was recently diagnosed with a life-threatening cancer. He was referred by HSC CancerCare Manitoba Centre. He had some experience with support groups in the past. His goals for this group were to learn what to do, how to manage his own feelings and to help his wife cope with this process.
- Erica was a woman in her 60's whose mother was in the final stage of a cancer diagnosis. She did not have personal experiences with a support group and had many other experiences with groups through her church commitments. The Home Care Hospice nurse referred her. Her goals for this group included meeting other people in similar circumstances, to gather strength for the future and tools to use to cope with the death of her mother.
- William was a man in his 50's whose wife of many years was in the final stage of a cancer diagnosis. He was referred by CancerCare Manitoba Centre. His experience with groups involved sports and work. He had no contact with a support group in the past and was concerned about being involved with this

group. He hoped to find other people in a similar situation to be able to talk with them and to learn about what to do to help with wife.

- Laura was a woman in her 40's whose daughter had a life-threatening cancer diagnosis. She was referred by CancerCare Manitoba Centre at HSC. She had previous experiences with groups through her church as well as a support group in the past. Her expectations for the group were high due to her sense of isolation from her family and friends. She hoped to learn new methods to cope, to find understanding from others, and to have a place to care for herself.
- Nancy was a woman in her 40's whose sister had a life-threatening diagnosis of cancer. She was referred by SBGH CancerCare Manitoba Centre. Her experience with groups was primarily with church and board of directors. Her hopes for this group included being connected with other people in similar situations, a chance to be heard and to learn how to do things differently.
- Denise was a woman in her 20's whose husband was just diagnosed with a life-threatening cancer. She noticed a poster at the HSC and contacted the student. She has had experiences with groups through work although none of them have been with her receiving support. Her hopes for the group included gaining confidence, a sense of normalcy and to break the isolation of her experience at this age.
- Connie was a woman in her 50's whose husband was in the final stage of living with cancer. CancerCare Manitoba at SBGH had referred her to the group. Her

experiences with groups were limited to family and school. Her hopes for the group were to receive strength and encouragement.

- Tanis was a woman in her 30's whose mother was diagnosed with a life-threatening cancer. She was referred to the by the HSC CancerCare Manitoba Centre. Her goals for attending the group was to find support, to not be judged by the group and to gain insight into how to help her mother through this time.

Participant relationships. "Cancer Caregivers: Here & Now" was a multifamily group with more than one caregiver from two families attending the groups. In Group 1 there was a husband and a sister of someone and in Group 2 there was a husband and a daughter of a woman. As revealed in the literature review, even family caregivers who have full responsibility for the care of their loved one, do participate in groups and do make the commitment or changes in their schedules needed to facilitate their attending the group regularly (Cherubin et al., 1998; Ostwald et al., 1999).

**Table 1: Group I Participants**

Participant	Gender & Age	Attendance	Relationship	Length of Relationship	Diagnosis	Length of Caregiving	Timely Death	Palliative Care
Barbara	Female in her 60's	5	Sibling/Sister	47 years	Breast Cancer	18 months	No	No
Mary	Female in her 30's	5	Partner	3 years	Brain Cancer	2 years	No	No
Wayne	Female in her 60's	1	Sibling/Sister	60 years	Brain Cancer	13 months	No	Yes
Susan	Male in his 60's	1	Partner	42 years	Brain Cancer	13 months	No	Yes

**Table 2: Group II Participants**

Participant	Gender & Age	Attendance	Relationship	Length of Relationship	Diagnosis	Length of Caregiving	Timely Death	Palliative Care
Nancy	Female in her 40's	5	Sibling/Sister	43 years	Breast Cancer	3 years	No	No
Denise	Female in her 20's	1	Partner	.25 years	Leukemia	.25 years	No	No
Connie	Female in her 50's	2	Partner	30 years	Melanoma	1 year	No	Yes
Laura	Female in her 40's	3	Daughter	22 years	Bone Marrow Cancer	2 years	No	No
Tanis	Female in her 30's	5	Mother/Parent	35 years	Brain Cancer	5 days	No	No
Michael	Male in his 60's	5	Partner	40 years	Brain Cancer	5 days	No	No
Erica	Female in her 50's	5	Mother/Parent	58 years	Breast Cancer	6 years, .35 years full-time	Yes	Yes
William	Male in his 50's	4	Partner	30 years	Brain Cancer	1.75 years	No	No

Group size. Group size became an issue with the first group. Between the first and second sessions, one relative died, thus two group members did not return to the group which left only two remaining members. At that time the decision was made to continue with the group since the remaining members were willing, the co-leader was committed to being there, and the advisor accepted it. With this commitment from the group, the content of the sessions was modified to recognize the limitations of such a small group.

The second group began with eight members. After the first session, Denise the youngest member, stated she was not ready to be in the group and did not attend the next session. Connie did not attend after the second session due to her husband's failing health and she reluctantly withdrew. The remaining six members attended the sessions as they were able.

The literature pertaining to the preferred size of a group was consistently clear, the more sensitive the topic the smaller the group size. Toseland & Rivas (1998) indicate that the size of the group should be based on the purpose of the group and the needs of the members. They consider a range for group membership from 3 to 15 members, with seven being considered an optimum number for a treatment group. Due to the sensitive, emotional focus, a smaller group is preferred in order to maximize the opportunity for each member to participate (Toseland & Rivas, 1998).

## Planned Structure of Group Intervention - Content & Topics

### General Format

The weekly sessions were planned to use a combination of experiential and narrative approaches to group social work intervention. These approaches were blended in an effort to engage the heart and mind of the family caregivers within the short-term group experience. The range of issues included communication skill development, how to express feelings, loss, abandonment, strength recognition, decision-making, cultural issues related to illness and death, spirituality, stress management, experiences with death, expressions of grief, talking to children, resource information sharing etc. Each week there were focus topics from which the co-leaders planned their intervention. The topics were caregiver stress, caregiving family history, communication, grief, and, healing touch and saying good-bye. Further details are found in the intervention plan as it was proposed (Appendix E). How the practicum sessions changed will be discussed later in the report.

The following section outlines the structure of each group session.

Opening. Each week the group gathered informally prior to the time for the session to begin. There were beverages available for the group members and music was playing to help set the tone of the evening. Once everyone was seated a moment was taken to actually listen to the music as a method of changing focus.

The use of music would vary within the five weeks. Initially it would be a quiet background, which invited people to relax into the meeting space and gave the group members something casual to talk about while awaiting the beginning of the



group. Then music was planned to be incorporated into the sessions as a means to provide subtle relaxation instruction and develop an awareness of their body. It was also planned to be used as a suggestion for bringing comfort to their loved one and a means for reminiscing with them (Attig, 2000; Byock, 1997; Smith, 1997).

To begin each week there was self-introductions, a check- in process that took approximately 20 minutes. Within this time group members took a few minutes to inform the other group members about how their week went, whether or not they thought about the previous week's group experience or attempted the activity that was given for consideration.

The opportunity to build an awareness of self into a caregiver's focus begins their self-care (Byock, 1997; Klein, 2000; Ponder & Pomeroy, 1996). This process of checking-in with the group was also an opportunity to check-in with their body and mind. The weekly check-in notes the passage of time. Often family caregivers are so immersed in the process of caring for their loved one that they are oblivious or withdrawn from the life around them (Klein, 2000).

The checking-in process began the connection between the group members and opened up the social interaction. This moment of communication began the exchange of meanings and symbols, an opportunity for patterns to be discovered between caregivers (Toseland & Rivas, 1998).

Experiential activity. Each week the practicum social worker described the session's focus and introduced the experiential activity. The instructions were concise and the process was explained clearly. The chosen activity took approximately 10 to 20 minutes to be completed, done individually, in pairs, or as a

group. These activities had been chosen from a book of therapeutic exercises for groups, to facilitate the weekly discussion (Dossick & Shea, 1988).

In each session the focus for discussion was facilitated by the experiential activity. It was to activate the process of learning and generate insights for the discussion. The experiential activity was planned as the creative process that facilitated a shift in focus, which led to different solutions to the caregivers' challenges (Bohart & Tallman, 1998; Greenberg & Balen, 1998).

Discussion. The co-leaders guided the group intervention for approximately 30-40 minutes, beginning with insights from the experiential activity. The intervention approach was narrative, as described in the literature review. Each group member had opportunities to respond to the questions as they felt comfortable to do so in the group and group members were encouraged to nurture each other as well with their insights.

In the group process, the co-leaders sought evidence of learning, new insights, and connections between group members. The social workers worked to confirm, clarify, and support the connections between the group members' actions and emotions. Together an awareness of the caregiver's needs, emotions, and new plan of action were discovered and confirmed (Ettin, 1994; Greenberg & Balen, 1998; Toseland & Rivas, 1998). Within the group process a construction of shared meanings was developed and explored as a means to affirm the group identity (Ettin, 1994).

Homework. As a method to encourage on-going reflection and to build on the evening's group experience, suggestions for actions during the week were

offered for consideration as homework. The suggestions included, for example, sitting and listening to music for five minutes once a day, writing their thoughts or feelings into a journal or having a conversation with a family member about sharing responsibilities, etc. These opportunities were planned to be a starting point for the following week at check-in in an effort to link the weekly group experiences.

Over the course of the five-week group, tasks were offered to the group members to consider completing, in light of the group experience (Appendix F). These tasks augmented the focus of the group and built on any insights generated from the experiential activity or period of reflection. In view of the narrative approach to the group, the concept of “homework” did not fit in with the non-hierarchical, position of leadership. Therefore the label of “considerations” was chosen (Gladding, 1998; White & Epston, 1990).

Closing. At the end of each group session, individual comments about the group experience were offered. These words reflected the insights achieved, moments of shared experiences with other group members and words of appreciation. The plan was for the music to be played to ease the silence of thoughts not shared and assist with the transition to leaving the group and saying good-bye. Each week good-byes were said formally with the intention to model the process of ending the connections with each other. It was a simple exercise, which facilitated the learning process of how to say the final good-bye to a loved one.

The process of saying “good-bye” each week was purposeful. It was an opportunity for the group members to practice how they manage endings (Attig, 2000). The lost chance to express their feelings or leave their loved one without

saying good-bye, is recognized as one of the most haunting issues that family caregivers live with (Attig, 2000; Byock, 1997). Living with anticipatory grief is particularly difficult because of the great, unknown factor of when death will come (Attig, 2000; Rolland, 1991; Rando, 1986; Walsh & McGoldrick, 1991). Yet people have difficulty saying good-bye on a regular basis. To therapeutically intervene, the co-leaders addressed the group member's leave-taking styles and offered an opportunity to explore other methods of saying good-bye. The "little good-bye" to group members recognized the passage of the five-week group (Toseland & Rivas, 1998). It also helped to recognize the advent of the final good-bye to their loved one. The social workers facilitated the process, encouraged members to express their feelings, and helped the family caregivers to anticipate how they might choose to say good-bye to their loved one when the time comes (Attig, 2000; Byock, 1997; Toseland & Rivas, 1998).

### Therapeutic Approaches

The strength based, non-hierarchical focused narrative therapeutic stance created a nurturing, kind, and compassionate position to explore and support the needs of family caregivers. The narrative position of "not knowing" facilitated the personal growth and development of the group participants (Cheung, 1998; White & Epton, 1990). Their experience of feeling out of control and struggling with their family situation meant that they responded very well to the opportunity to learn about the choices for self-direction and reflection on their caregiver role within their

families. The non-hierarchical position, a “non-should” position of the social workers, supported and empowered the family caregivers to make decisions based on their needs and within the context of their relationship with their loved ones. An example of these choices would be the new decision to delegate household chores to other family members in an effort to re-direct their energy more toward the dying loved one. As well, the family caregivers had an opportunity for altruism with others in the group and broadening their point of reference (Holland & Kilpatrick, 1993; Rutan & Stone, 2001; White & Epton, 1990).

The narrative approach guided the family caregivers to consider their established level of ability as a caregiver and to discover their roots for it, by telling stories from their past about how their families function as caregivers. These stories revealed their strengths in other situations of adversity, family patterns in coping and the individual exceptions in the process (Eron & Lund, 1996; Kelly, 1995; White & Epton, 1990). When these strengths were discovered, the social workers were able to explore the caregivers’ challenges in their current situation. By asking questions and creating a space for the group members to collaborate with each other, the co-leaders guided them in making decisions about future goals for behaviour in caring for their loved one with a life-threatening diagnosis and in taking care of their own needs. The group participants felt the benefits of empowerment as did the loved one with compromised health, as shared within the group discussions and reported by collateral professionals.

The experiential homework (considerations) also represented a tangible focus for the family caregivers to recognize the possibility for change and the chance

for self-care even within very limited time periods. The social work group brief intervention allowed for their sense of isolation to be diminished with the knowledge that they are not alone in their feelings and experiences of being a family caregiver. As well the weekly sessions created a benchmark for their development and recognition of time passing. The narrative position created an openness for the group participants to direct the process of the group within the framework of the group's focus and to achieve a sense of empowerment, which provided them with further confidence to manage their lives as family caregivers as they navigate the eventual palliative care process with their loved one. The established curative factors for group intervention were recognizable within this experience (Smith, 1999; Toseland & Rivas, 1998). The high level of catharsis, altruism, cohesiveness, sense of universality, and self-understanding, confirmed the practicum goal of providing a significant social work intervention for family caregivers. Their ability to collaborate with each other about their experiences and opportunities to share information about being in this role facilitated their sense of personal agency and feelings of empowerment were generated.

### Changes in Practicum - Plan to Reality

The practicum student and co-leader realized very quickly that the amount of planned activity for each group far exceeded the 90 minutes of time for each session. As well, there was the participant's need for the exchange of stories and discussion around the focus topic, which caused a review of the practicum plan.

With the guidance of the advisor, the co-leaders revised the plan for each session to make it possible to have the discussion within the group and the experiential activity as a “consideration”, which the group participants could complete during the week between sessions. Then, each week began with a check-in followed by a discussion about the “considerations” and any reflection about that activity. The other actual experiential activity attempted in the first group was a role-play and sculpture to symbolize the struggle within a family. The introduction of the activity and the experience itself created more of a feeling of interruption than it was a benefit to the session. Consequently it was not attempted within the second group process partly due too to the room configuration, which did not allow for any movement or role-playing since it was set-up as a boardroom

Music. Frequent use of music was part of the original practicum plan. It was going to be used to create a setting, an atmosphere of comfort. However within the planning stage with the practicum committee, it was determined that the frequent use of music could create comfort for some participants and discomfort for others. Consequently the use of music was greatly reduced. It was offered in the last session only, before it began and during the final activity. The decision to introduce it at that time provided an opportunity to present it as a means to bring comfort to the individual and their loved one, to use it as a means of reminiscing, and, for use in reducing stress (Attig, 2000; Byock, 1997; Smith, 1997). As well it was intended as a method to create a private space between group members as they expressed their final thoughts and feelings in the final activity in the last session.

The group participants indicated that they were already familiar with some of the concepts regarding the use of music. The idea of using it to remember the past times of dancing or singing was well received. However, in the second group, members found the music to be intrusive and distracting to what was going on within the group. The feedback focused on it inhibiting their ability to attend to what was being said and that it was not necessary to have it due to their comfort level with silence. The members did not feel the need to create a barrier (music) while they worked in pairs during the closing experience. The choice of music is a variable to consider when determining the effectiveness or ineffectiveness of it.

Content. In the practicum plan each of the groups had specific topics. As the group process began or developed, the co-leaders made decisions to adjust the themes or the timing of them within the group process. The first session's focus was designed to attend to the level of caregiver stress. However, when it came time for the first session of the first group, the co-leaders assessed that the group needed to talk about their individual situations and to tell their stories as a method of developing group cohesion. The second session became a combination of recognizing caregiver stress and the family history of caregiving. Visualization was planned to assist group members with remembering childhood illnesses and who took care of them. In Group 1 the visualization was changed to a few moments of reflection before the co-leaders moved the group into a reflection of their thoughts and memories. This change was a result of the co-leaders assessing more value in the group members' need to talk to one another than be held in a visualization. In



Group 2 the same decision was made and a brief visualization with time for reflection was used instead.

The third sessions were planned with a focus on communication with a body sculpting activity to illustrate the body language we have as well as verbal. In Group 1 the session was completed as planned and it was somewhat awkward in the group process. In discussion with my advisor, the communication theme for Group 2 was augmented with a discussion about Ira Byock's "five things to say"(Byock, 1997) instead of the body sculpture. The five things to say include: I love you, thank you, forgive me, I forgive you, and good-bye. The co-leaders facilitated discussions about each of the five phrases. Further discussion about these sessions will occur later in the report.

As it came time for the fourth session, the planned experiential activity seemed inappropriate. Consequently in Group 1 the fourth session's focus was changed to Byock's five things to say. It blended well with the theme of communicating with their loved one about their relationship and to develop an understanding about grief and loss. Byock's five things to say gave the session a framework from which to discuss the opportunity to clarify the relationship with their loved one and to help shape the remaining future they have together. This change in focus also was more sensitive to the family caregivers' needs. It became evident to the co-leaders that it would be insensitive to proceed with the planned activity because the group participants were well aware of the many losses in their lives, understood their level of grief and needed something to assist them in their

remaining time with their loved one. The adjustment of this session proved to be quite beneficial and created a significant experience for the family caregivers.

The fifth session in both groups was conducted in the intended manner. The typical check-in proceeded and the plan for the session was explained with the experiential activity sheets. Music was played during the time the group members worked in pairs. The length of time for the group evaporated into the intimate discussions and did not seem to be enough for the group to finish. The work in pairs created an opportunity to recognize the significance of individual connections between people and it evolved into a group process, which was emotionally contained with poignant words describing the significance of the group as a whole.

Experiential activities. The original plan for the groups included weekly activity sheets to be completed within each session to assist with the focus of the reflections, to build group cohesion, and to promote emotional expression (Ettin, 1994). However, it became apparent that there wasn't a need to artificially stimulate group cohesion or emotional expression nor was there the time to include these experiential activities within the sessions. The co-leaders were able to quickly assess that the group participants needed to express themselves to each other relating to the session's focus and that the activities would not be an appropriately timed experience within the ninety minute sessions.

Another aspect of assessing the use of the activities within the group included a therapeutic perspective for the timing of the activity within the process of the practicum. The concept of these planned activities did not blend with the reality of a brief, five-week group intervention. The co-leaders sensed the intense relief of

the participants, to be together and express their emotions within an understanding environment, and chose not to direct the flow of the dialogue through activities during the group sessions. In the first group, in an effort to be true to the practicum plan, a small role-playing was created to illustrate the family dynamics of one of the members. The time it took to construct the activity was a distraction from the process and the group dynamics. From that experience the co-leaders determined that the role-playing activity would not be considered for the second group process.

However the value of the experiential activity was translated into "considerations". A selection of the planned experiential activities were offered to the group members to be considered as a means to connect one week's focus with the next week's experience (Appendix F). The activities became an example of self-care when participants were actually able to take the time between the group sessions to think about or actually complete the suggested task. They became vehicles of change within the group process and an opening to indicate where their week had taken them at the check in. Participants in both groups varied in their ability to complete the activities. Within that experience of differences, the co-leaders had an opportunity to reinforce the acceptance of differences, demonstrate understanding for the complicated life situation the members were living, and, support individual processes of learning and self-care (Bohart & Tallman, 1998; Walsh, 1998; White & Epston, 1990). As well the thought was reinforced that everyone would respond to their loved one's illness in their own manner and come to terms with it in their own characteristic way.

Group norms. As with any social work intervention, a preliminary discussion took place regarding confidentiality, respect, punctuality, and, listening. Within both of these groups, the members showed a high regard for irregularities to the group norms, to the point that it became a group norm. The participants accepted the need to have cell phones left on, "just in case". The strong sense of being "on call" as family caregivers became a theme for both groups. Consequently, the possibility of being called was an accepted reality and they were able to quickly determine if the call was important enough to interrupt the group process or to briefly respond to it. When someone was late or unable to attend due to illness or an unavoidable appointment, it was fully understood and supported. The level of acceptance for the "roller coaster" ride of being a family caregiver was quite high and was even extended to the co-leaders when one of them was late for the group.

This level of acceptance for events which interrupt a planned process, a ninety minute support group, was an unanticipated learning opportunity. The practice of creating and enforcing agreements within an individual or group session, regarding participation, attendance, confidentiality etc., are quite central to any type of social work intervention (Rutan & Stone, 2001; Toseland & Rivas, 1998). In these groups, the participants concurred with the typical policies of being on time, keeping information about each other confidential and being respectful in their interactions. Then the reality of their lives as family caregivers to people with a life threatening illness intervened and the need to be flexible presented itself based on the participants' accepted reality. Their intrinsic belief in each other was evident. They believed that each member of the group was capable of setting priorities and

accepted that when it was possible to be on time for the group that they would be. If they were not well enough or unavoidably absent they would be missed and offered understanding when they returned. Consequently the co-leaders were moved to support this position of acceptance within the therapeutic process and manage it by providing summaries to latecomers or people distracted by a telephone call, or clarification about the time to end.

### Session Descriptions & Goal Achievement

This section presents a session by session description of what occurred each week and to what extent the overall group goals were achieved by each session. The discussion includes commentary about the changes made in the practicum plan and the impact of these changes. Events from both groups are integrated in the following discussion.

Session I. Most of the family caregivers arrived on time for this session and were welcomed by the co-leaders who invited them to help themselves to the refreshments. When everyone was settled in the circle of chairs, the practicum student officially welcomed them to the group, thanked them for coming and outlined the session. She explained the check-in process as a way to briefly introduce themselves with their names and the name of the person in their lives who had cancer.

The co-leaders carefully elicited participants' perspectives on what was required to create a comfortable group climate. Issues around confidentiality were

discussed and clarified to confirm the integrity of the sessions, as well as the expectations around attendance, promptness, and goals for the group. Once these policies were created the co-leaders invited the group participants to offer their stories about being a family caregiver. They moderated this session carefully in a strength-based narrative manner with words of affirmation for the members' willingness to participate, their risk-taking, their caring, and for their openness to each other. They took a clear position of "not knowing" from which to ask questions of clarification. The co-leaders acknowledged that there are separate and different ways to be family caregivers, "unique points of view", which are all acceptable for expression in the group.

Because this approach and process took a significant amount of time and the participants obviously had a high need to discuss their situations, the experiential activities, which were planned for this session, were relegated to a homework assignment. The co-leaders integrated the topic focus of caregiver stress and recognized that participants had their hands full with different responsibilities. The discussion was rich with the sharing of stories of their busy lives as family caregivers. This focus was also a means of preliminary introduction for the homework assignment.

When the discussion about the stress of being a family caregiver came to a conclusion, the practicum student invited the participants to make a closing remark. It was explained as an opportunity to offer any thoughts or feelings about the experience of the session and it would be a regular part of the weekly sessions. Barbara stated, "Being here was not as scary as I had expected." Laura also said,

**“That felt good. It was like a time out. Now I am ready to go visit my daughter.”**

**After the closing remarks the practicum student distributed the experiential activity sheet. It was the outline of a hand. (See Appendix F). Then she instructed the group to fill it in by writing or drawing what constitutes their handful of responsibilities, to be received in the next session.**

**The first group goal was to relieve, and normalize the process of suffering for the family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups. In this session with both groups, there were significant indicators to confirm achievement of this goal. The primary indicator was the number of tears shed in each of the first sessions. This action was interpreted as an indication that the group participants felt relief, comfort, and a level of understanding from the other family caregivers and co-leaders. Another indication was the flow of discussion between the group members after they had initially told their stories. The similarity of issues confirmed the sense of closeness experienced by the family caregivers which was also evident in the manner the participants left the group, in two's and three's.**

**The second group goal was “to engender confidence within the family members to be able to communicate openly with their loved ones and professional care providers as developed through the group experience of shared knowledge and feelings.” The group experience of openness and acceptance of differences facilitated achieving the beginning of this second goal in the first session. The gentle, caring approach of the co-leaders, as demonstrated by the narrative approach, supported the family caregivers' efforts to express their concerns openly**

with each other. This approach supported the family caregivers' efforts to ask each other questions and to present their experiences with other family members for discussion within the group.

The third goal was "to support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs." This topic was not overtly discussed within the first session and yet it was an underlying theme of the topic of caregiver stress and how to be available to their loved one in a way which is characteristic of their relationship. It was introduced as a reminder of their former relationship with their loved one and how they can relieve themselves of some of their caregiver responsibilities to continue their relationship in a meaningful manner. Within that session the third goal was addressed as well.

As the fourth goal was about evaluating "the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people", for the first session it was a beginning point of gathering this information. In this first session, even considering the typical level of politeness in a first session, the caregivers' experiences of relief were evident in the amount of tears shed, the warm laughter, and the clarity of revealing comments in member to member interactions during the group. This provided initial evidence for achieving this fourth goal.

Session II. The focus of this session was the family history of caregiving. There was a similar format with an initial check-in which led to a discussion of the homework. The experiential activity from the previous session was completed in a



variety of ways, with group participants filling in the hand with writings, colouring it or not filling it at all. It generated a long discussion about how they each responded to being a family caregiver.

The variety of responses inspired various comments of understanding from the other participants as well as humour. William, who did not complete the hand wanted a “detention” from the “teacher”. Then Michael admitted to not knowing what to do with it but realized that it represented his confusion and that he had a handful of “conundrum” due to his wife’s recent diagnosis. This activity gave him an opportunity to realize that he had a handful of not knowing, of too much information, not enough clarity to know what to do with it all and that is what caused his “foggy state”. At the end of this session he warned everyone to be careful driving because he felt he was impaired and had been extra careful in recent days.

The group comfort level was maintained by the facilitator’s acceptance of the fact that the homework task was done differently than originally described or not done by each group member. It became a platform for further discussion about what they do as caregivers, how they feel “on-call” all of the time, how their lives have been dramatically altered by their commitment to their loved one, and, how they are constantly juggling their needs with those of others. When the discussion shifted to focus on how to relieve the fullness of their caregiving by asking other people to help, the sense of the lineage of family caregiving was determined through their stories. These narratives provided the co-leaders with information about how strong a family tradition their style of self-less caregiving was in their family. It also revealed the tradition of no time for self-care while caring for someone who is dying.

The “here and now” focus of the narrative approach facilitated the decision-making process for the co-leaders with the second session of the first group when two people withdrew due to a death. The co-facilitators maintained their focus on the group members who discussed their homework and offered stories which responded to the theme for the session. When there was a natural bridge to introduce the reason for the other members’ absences arrived, the practicum student told the group members and moved into the conversation around the many issues that occurred to them. They discussed how it felt to have empty chairs, the suddenness of death, not knowing it would be so soon, on the facts surrounding her death (as was printed in the obituary), and how it affected them. The members related this event to their lives and how they would be ready or not yet ready to face their own empty chairs etc. The co-leaders recognized the similarities and differences in their responses and normalized the process for each member.

In both groups the overall focus on the group as a whole was specifically directed by the co-leaders on building the acceptance for diversity of caring ways within the group and their families. This clarification provided the participants the opportunity to openly discuss their situations and recognize their responses to it in a respectful environment. There were expressions of frustration with other family members and well-meaning friends that “just do not get it” about the seriousness or about the impact of dealing with loved ones’ illnesses on the caregiver. Consequently the sense of relief was palpable within each group as this understanding acted to cohere and free them to express their feelings about these people.

As a way to focus their attention on what nurtures them, the experiential activity was a drawing of a room (Appendix F) which they could fill with anything that supported them to be healthy happy caregivers. It was explained that they could draw or write or think about it in the following week and present the results in the next session. Then the closing comments were offered to the group. Michael noted that he was managing the roller-coaster ride much better and it was not so much of a "tearjerker" lately. Nancy, with her wry humour noted that she did not remember "signing up for this cruise" and that she was glad to be on it with this group, a place to let the tears roll down her face without reproach. Mary also noted that she was glad to be in this group where no one "judged" her and she could talk freely.

The co-leaders facilitated this process by illuminating the choices available to the participants in their response to these people in their lives. The choices were gleaned from the group members' responses as well as others known to the social workers. The effective validation from the co-leaders and then the supportive comments from the participants to each other created an empowering focus and motivation for the group members to actively be aware of options and opportunities to modify their behaviour.

As revealed in the above material the four goals of the group were more fully realized. The group continued to experience the relief by being together, they were gathering confidence to speak more openly about their needs with their families by discussing them within the group and they were beginning to gain a sense of direction and affirmation for their care-giving style. All of these experiences, within

the second session, began to formulate the support for an on-going support group for family caregivers which would be the fulfillment of the fourth goal.

Session III. The theme of the third session was communication. In both groups the check-in included comments about how the loved one's week was, how many doctor appointments or trips to the hospital. The pattern became evident that the family caregivers' week was directly related to how their loved ones' weeks were. There were more comments to indicate an increase in their awareness of the "shoulds", "have to dos" and of being "on hold". Their increased awareness of their needs raised some questions about self-care being different than being selfish.

The presentation of the self-care rooms was quite illuminating in the similarities among stories. Many participants had music, books to read for pleasure, plants and comfortable chairs. There were comments about how much time they spent thinking about their room. Most of the rooms were without any other person or animal in it. Barbara commented that "I would probably get bored with it. Although I would kind of like an opportunity to be bored". This experiential activity was quite effective in eliciting plans to adjust some aspect in their actual rooms or their lives to accommodate a nurturing space. Laura described her space to the group as a big chair with a special blanket in a sunny window from which she can look at her garden. Michael talked about his kitchen as being his space and how he became aware that he needed to plan to spend some time in it soon. This activity opened up their awareness to the possibility of incorporating self-care in their ordinary routines. Erica, visiting from out of town to be her

**mother's caregiver, actually changed the room she was using and reported a benefit from this activity.**

**The narrative intervention consisted of recognizing the exceptions and possibilities of finding time to nurture themselves, to assist in the acceptance of a new individual narrative. The family caregivers' traditional narratives of wanting to be selfless in their efforts to respond to their loved ones were adjusted because of the reality of how stressful it is to behave in that manner and the opportunity to discover other ways to respond in the group process.**

**In the first group, this session included a role-play to illustrate communication within a family. The time it took to set it up and then to actually do it created more of an interruption than a benefit. Perhaps it was a factor that the group was so small and not familiar with that activity in a therapeutic sense. It became apparent that a similar planned activity to demonstrate different types of communication styles would also not be a good idea. Consequently the plan was adjusted to keep the discussion within the group using examples from the participants. This decision kept the focus on the here and now of their lives and the group process which was consistent with the narrative intervention plan.**

**With the theme for this session being communication, the idea of "not knowing" and the concept of "here and now motivation" came out of the discussion. It was discovered and confirmed within the group sessions that when family caregivers do not know what the future will bring they are motivated to more openly express their feelings with their loved one. The participants spoke of conversations where issues were addressed and resolved with their loved ones or**

conversations were initiated with other members of the family about the prognosis of their loved one. The family caregivers' range of experience with this style of communication was broad. Some participants had been open with their thoughts and feelings and other people were just learning how to do it. This gap of knowledge was bridged by the discussion of experiences by the group members. In this session, in both groups, the co-leaders' involvement was less than that of the first two sessions.

In the third session for the second group, we incorporated Byock's (1991) five things to say before someone dies. The group members were receptive to the discussion. They acknowledged doing the first two parts of it, saying, "I love you and thank you", but expressed difficulty with the concept of asking for or offering forgiveness to their loved ones for any past hurts. This difficulty illuminated the relationships as being very protected and not reciprocal in nature. The family caregivers stated in different ways the belief that "I cannot do that, they are sick after all". The fifth thing to say was "good-bye" and all but one was not ready for that; it was too soon.

The narrative response to these stories recognized how differently the participants managed their family situations and highlighting the changes they were making in their lives. Some participants were already expressive with their feelings and others were just beginning. Connie reported deciding to make a contract with a handyman to do odd jobs at her home that her husband used to do, tasks that she and her sons are not able to do. By making that choice she felt some relief in her day to day level of stress. Then Connie reported asking her sister-in-law to come to

the next doctor's appointment for her husband and to disseminate the information for her to the rest of the family. This was another choice inspired from conversations within the group and celebrated as an action toward self-care. The wide range of interactions and decisions to change were recognized, accepted and presented within the group as being different processes for each of them, not one right or wrong way to be family caregivers. In expressing this balanced position the co-leaders generated a sense of empowerment within the group. Typically family caregivers feel helpless in the face of a life-threatening illness and in this group they were discovering that they had choices: to gather strength through the ideas being shared in the group, to respond to their difficult situation actively, and to regain a sense of personal agency.

By revising the experiential activities in this session for the second group, the practicum student more actively responded to the participants' needs to connect with each other and to hear about their lives. The opportunity to talk to each other was a primary one which was augmented in the whole group by the co-leader's questions. For example: "How could it be said differently?" "How does that sound to you?" etc. At the end of this third session no experiential activity sheet was handed out. The group participants expressed their disappointment. The practicum student thought that perhaps the experiential activity was not required at this stage and the second group especially indicated the value of it.

The goals of this session were fully achieved. The group participants' level of confidence to manage their level of stress and heightened awareness about the process of anticipatory grief was evident in their comments and actions about the

changes in their lives. With further reflection about the use of role-playing, the practicum student concluded that the five-week intervention plan did not support the use of it so it was not used with the second group. The therapeutic value of role-playing was not achievable within a group that was barely formed and who were perhaps not comfortable with the initial therapeutic process. The family caregivers' ability to risk engaging in new behaviour was already being exercised by coming to the group.

Their commitment to the group confirmed their resolution to nurture themselves, as did their forthright request for information about the next session and request for a resource list. Their on-going expression of relief in being together weekly also underscored the beneficial experience of this intervention, another session goal achieved.

Session IV. The focus of this session was grief. Both groups opened with the check-in, although the members had already begun their check-in without the co-leaders. They were so interested in each other's news and how the week passed that they did not wait for the co-leaders to initiate the process. Since there was not an experiential activity sheet, the check-in and initial focus of discussion was about how they coped with their week and whether they had noticed any changes in their method of coping with their family situation.

Barbara told the group that one of the changes she noticed about herself was, "I am not rushing in to help with my answers. I actually suggested that she (sister with breast cancer) consult other people". The burden of decision-making was shared for the first time since her sister came to live in Winnipeg for the final days



of her life. Barbara's face was flushed with emotion as she told that story. She also told the group that she had signed up for an exercise class. Even though she did not know what the fall would bring, she wanted to make plans for herself, "I have learned to give myself permission to live."

In check-in in the second group, Tanis acknowledged a new insight into the doctor's challenges, "It must be hard to be a doctor, always telling people bad news." She went on to indicate her goal of finding a balance between caring for her mother and asking questions respectfully to the doctors. From the previous week's discussion she realized that her anger about her mother being sick was being directed to the doctor and to the co-leaders of the group and she asked for understanding with her apology.

Also in the second group, Erica told the story that she was "going crazy" at home waiting alone for her mother to die. She felt the need to call the family and her mother's friends to come for a visit now and not wait for the funeral. As a result of discussions in the group, she came to a decision to call a few people and invite them to spread the word that she would receive visitors with her mother. Erica was beaming with a smile as she told this story because "I'm going to see the whole family. They are telling me stories about my mother I did not know."

The addition of Byock's (1991) inspired discussion occurred in the fourth session of the first group. In a similar way to how the second group responded in their third session, this group made comments to the effect that they could not possibly offer forgiveness for any hurts they carried in their hearts that their loved one had caused. The narrative response of the co-leaders left it open to the group

participants to decide what felt natural for them to do within their relationships. Mary commented "I have been disappointed so often in the past and I do not have the energy to do that now." She acknowledged having done parts of the reconciliation process but was not prepared to do it all or to begin to say good-bye.

The family caregivers' sense of urgency often came through with their desire to "do it right". Their lives were full of appointments and panic that they were running out of time that this focus on grief and not knowing how much time they had with their loved ones really was intense in this session. The co-leaders were able to express a belief that the group participants would make a decision when the time was right for them. They very gently offered this perspective and it created a sense of relief that another set of professionals was not telling them what or how to do things.

The anticipatory grief of the dying people also filtered into this discussion. The group participants revealed having been questioned by their loved ones about the group. They expressed discomfort and confusion about how to respond. Various suggestions were given by the group members; such as "Tell them it is private." "It is time for me." "I assured him/her we are not talking about them the whole time." "It is help for me, do not worry." The co-leaders introduced the idea of self-care and comfort as a way to also respond to questions from their loved ones about the group. They also presented the concept of going beneath the questions to look at an underlying one about, "How are they caring for you in ways that I cannot?" The sense of separation was acknowledged and the discomfort of it

recognized as part of the experience of living with a life-threatening illness in the family.

The experiential activity was not used in this session due to the lack of time and diminished value of the purpose for using it. The group members had significantly bonded together and no longer required the activity to generate discussion. The co-leaders decided to not hand it out as a homework assignment either because it was considered unnecessary and a distraction within the final session.

In this session the co-leaders' roles were supporting the interaction between the group members as they kept the focus on grief. The level of discussion reflected the confidence and connections the members had within the group. This interaction represents the achievement of group goals. The group members' level of stress was lower as revealed in their comments and shared stories about the changes that they have made in their lives. Their new level of confidence was evident in the examples of decisions that they made. The fact that there was one more session was also mentioned and the family caregivers wanted information about the last session and what to expect. They needed to know, to prepare for it and they asked again for a resource list to take with them for after the group. This request indicated their sense of personal agency which was nurtured through the use of narrative intervention. The high level of comfort and support between the group members also endorsed the final goal of revealing the value of family caregiver support groups.

Session V. The focus of the final session was healing touch and saying good-bye. The last sessions began in the usual manner with the check-in up-date. By this

time in both groups the participants indicated how their week went and how they felt, then they talked about how their loved ones were. When it was time for the discussion the co-leaders distributed the experiential activity sheets with the pair of hands clasped together (Appendix F). Then the practicum student explained the plan for the session. The group members were instructed to meet in pairs to write on these sheet messages of appreciation, comfort and wishes for the future as well as talk about what the time together has meant to them. The student also explained the use of the music as a way to create comfort in the room and to fill in the space between the group members in their conversations. The group was also asked to change partners when it felt timely, at a natural point of ending and to be aware that we had approximately 45 minutes to move through this part of the session.

The surveys were distributed at the end of the first part of the session while some people were finishing their conversations in pairs. Most people were able to complete the surveys during that time and two people took their questionnaires home with them to complete at a later time and mail in. One of them has been received in the mail.

The group reconvened as a whole to comment about their experiences in session and overall. The fifth session was the only one where the planned experiential activity was completed in the group session. The picture of a pair of holding hands was used to facilitate the ending of the group. Another reason this session was an exception was the use of music. There was music playing throughout the process of closure to create a calm background, some privacy for conversations

between the participants, and, to be an example of how it helps within the quiet times when visiting their ill loved one.

A curative factor experienced in these brief five-week groups was the preparation and modeling of how to say "good-bye" each week and then ultimately to their loved ones. The sense in this session of being not ready, not having the right words or it not being the right time to say good-bye, was consistent with not being ready to experience the death of their loved one. This process caused some agitation for some members, a relief and comfort for others as they struggled to find the words to express their feelings.

The experience engendered confidence in the family caregivers, which was affirmed by the co-leaders, that they were able to rise to the occasion of saying good-bye when necessary and even under time restraints. To be able to practice saying good-bye symbolically to previously unknown strangers created a learning opportunity from which they will build on to prepare for their final experiences with their loved ones.

Another unique feature of this session that naturally transpired, in both groups and especially in the second group, was the amount of touching. Group participants were sitting closely on couches, holding hands, hugging or arm and arm as they gave and received the written comments. Erica commented, "We ought to have done this more often." The comfort with one another was validated and used to confirm their ability to similarly find the manner to say good-bye to their loved ones as well. The termination discussion in the groups revealed the depth of appreciation

for the time they had together and for this intervention which accomplished the final group goal.

This final activity was an example of a narrative intervention which is to write comments in a post-session letter to reflect on an individual's progress, to proffer encouragement and support for the changes and challenges of the individual's life (White & Epton, 1990). With the group intervention this feedback took on a different shape in the final group exercise of writing notes to each other. The unique nature of these notes, a combination of reflections from the co-leaders as well as the other group members, extended the narrative concept of collaboration and nonhierarchical involvement of the co-leadership. The words of strength, wisdom and encouragement were augmented by the various points of view in each message from other family caregivers and social workers. The notes became gifts to take along on the journey of living with someone who has a life-threatening illness and words of affirmation to remind people of their ability to cope with that process.

The experiential activity used in this session functioned quite well to facilitate the final discussion process between the group leaders and participants. It also became a treasure to hold onto to remind the individuals of the messages from the other caregivers to help them along the way with their loved ones. The activity gave the group members a focus and it helped to contain the process of closure. In this situation it assisted the group process and achieved the purpose to assist with the termination of the groups.

The description of this session and the client satisfaction survey results confirmed the goals of this session were met and surpassed. The family caregivers

had bonded with one another and were able to confidently share their feelings about each other in the final experiential activity. The stories they told about their relationships with their loved ones confirmed the development of their relationships were due to the group intervention. The group members also mentioned how they cared for themselves currently and what their plans were to care for themselves in the future. They expressed their appreciation for the group to the co-leaders in writing and with small gifts to the whole group.

### Stages of Development

Rutan and Stone (2001) indicate the expectation that short term group intervention allows for participants to focus on specific issues without the possibility of long-term dependence. It is also understood that the stages of group development are condensed and hastened by the brevity of the short-term intervention plan. There are many names given by therapists to describe group development: Schutz's (1958) inclusion, control, and, affection; Bion's (1961) flight, fight, and, unite; Tuckman's (1965) forming, storming, norming, and, performing; Yalmon's (1985) orientation, conflict, harmony and, maturity (Smith, 1999). For the discussion here the simple description of beginning, middle and ending stages will be used as generic descriptors used by Toseland and Rivas (1998).

Beginning stage. With both groups the initial conversation focused on their challenges in finding a parking place, the weather and pleasure in having refreshments available. The practicum student began the session by recognizing and normalizing the sense of anxiety. In brief intervention groups the social worker

stance is fairly active to maintain the focus of the sessions (Rutan & Stone, 2001). Consequently, the group was given the basic information about the format of the session, check-in was explained and the co-leaders allowed people to begin when ready to speak to briefly introduce themselves. The co-leaders left it open to the group members to decide who would speak first. In each group there was a time of silence while they gathered up the courage to speak.

Each person in the group was guided to say his/her name and to indicate who in his/her life was affected by a type of cancer as a simple introduction. To avoid participants being flooded by emotion, the co-leaders limited the initial introduction descriptions. Then a discussion took place about what group policies would need to be established to create a comfortable setting to talk more freely about their situations. The standard concepts of confidentiality, respectful behaviour, and being on time at the beginnings and endings of group sessions were confirmed.

The intriguing difference regarding group policies for the family caregiver's group was the discussion around cellular telephones. In the first session of the first group, a cellular telephone rang. The interruption caused the group to pause and wait for the conversation to be completed. The introduction of this topic was very appropriate and timely. With sincere apologies the person turned off the telephone and put it away. The participant did not feel the need to have it on. In the second group a similar situation occurred as in the first group and there was no apology for the interruption. There were eight people in the first session of the second group, three people had their cellular telephones visible or were holding them. It



represented their sense of being “on call” and on alert for their family members. The groups accepted the interruption, as a fact of life as caregivers and it was a mutually understood situation, which was more manageable than the thought of turning the cellular telephones off. The group members spoke about how there was a “code of conduct” for people in their situation. They recognized the variations of their contact with people in the hospital or in the community, to say only “hello” or to strike up a conversation about their recent days.

These examples of the mutual and deep understanding for each other due to their common experiences with life-threatening illness in their families, meant that the two groups cohered immediately within the first session. The universality of the type of experiences they shared plus their belief in themselves to do whatever it takes to help their loved one helped them engage in the group process immediately. The co-leaders facilitated this recognition further by drawing attention to these details within the introduction and context of the session when the group members were relating their stories. Further evidence of the groups’ cohesion was the sense of relief expressed through the amount of tears shed within the first sessions of both groups and the individual group member’s comments about his/her sense of relief. The level of comfort, the experience of breaking the silence about their needs and feelings, resulted in an immediate sense of trust in the groups. It is one of the advantages of time-limited intervention when the homogeneous nature of a group accelerates the early stage development of trust, cohesion and self-revelation (Rutan & Stone, 2001).

The process of getting to know each other carried over into the second session of each group. The participants were very comfortable with each other, they spent time "checking in" about each other's week before the official beginning of the group. The initial tone of this second session of the groups indicated that the beginning stage felt completed by them and the middle stage of group development had begun. Their focus on being there to work, learn and be supported shifted them immediately into the middle stage of group development.

Within the second session in both groups, the sense of caring for each other was quite recognizable. There were frequent questions of clarification, long periods of listening to each other, silent reflection, space between each other's stories and expressions of genuine concern. The family caregivers' altruistic nature was intrinsic to the group, they cared for each other in a manner similar to how they cared for their ill family members.

Middle stage. Again, this session began in the informal conversation between the members in each group before the co-leaders initiated the session. The high degree of interest in each other's week and the health of their family member was genuinely expressed and responded to empathically. When the co-leaders introduced the topic of session three and the concept of the time line, the groups' sense of time passing and the future ending was evident. One of the advantages of short-term intervention that Rutan and Stone (2001) list is the focus on loss and separation. The family caregivers were mindful of the limitation of their time within their family and, the group's duration. When the co-leaders verbalized the mid-point of the group intervention, the sense of surprise was expressed. The group

participants were amazed at the passage of time and the closeness that had developed with the other group members. They renewed their commitment to attending despite feeling emotionally over-extended because of the nurturing provided by the group. The high degree of value for the other group members and the group process was affirmed in this session when the end was acknowledged.

The typical early group events of conflict, resistance, dropouts etc., that occur within a new group were not evident (Rutan & Stone, 2001). Since these were homogeneous groups, the cohesion was strong and the non-judgmental stance of the co-leaders promoted inclusiveness and reduced any potential conflict within the group. The nurturing setting and tone of the group allowed for a relaxed environment which created a supportive place for the family caregivers. They often reflected on the sense of "being on the same page" with one another. Consequently, the only reason why people left the group early was due to their loved one's critical state or death. The group members were consistently on time, focused on the topic and willing to participate in the discussion.

Ending stage. "What are we learning today?" A participant in the second group asked this question in the beginning of the fourth session. The sense of urgency and limitation of time was underscored by this question. It was asked as soon as the co-leaders took their places in the circle of the group. The heightened awareness of the group's ending was supported and related to the family caregivers' situation. The fact that the group had a specific time to end was seen as a gift to the members in that they knew when it was happening. The realization was comforting for them because there was a concrete time for termination within this context

which felt better than the not knowing end for the life of their loved ones. As well, the group members made choices about how active a role they took within the groups in an effort to maximize their opportunity for supportive social work intervention.

The group participants were quite forthcoming with examples of changes they had made in their lives and their improved level of self-confidence was evident in the description of changes made in how they managed their situations. The group members were able to reflect on the changes in one another and their degree of support was genuine and high. In the fourth session the co-leaders guided the groups' interaction to maintain the focus of the group, yet there was a sense of being superfluous. The interaction was balanced between the members, there were companionable silent moments, warm laughter and gentle challenges within points of clarification between them. The typical level of resistance within a group in the middle stages was not experienced pervasively. A member of the first group was consistently resistant (consistently not following through with the "homework", not being open to any suggestions for self-care etc.) and it was considered a method of coping with her overall situation, not specifically in response to the caregiver's support group.

The awareness of loss and endings was consistently expressed throughout the group process given the focus of the support group. Consequently, the typical emotional response to endings within other short-term group interventions was not determined to be a characteristic of these groups. Certainly the sense of apprehension or sadness was expressed by the participants however within the

context of their family member's life threatening illness, the groups' conclusion paled in comparison. Also, the support group members had begun to discuss how they would continue to support one another after the group disbanded which gave them a sense of continuity and limited the fullness of their loss.

In the concluding session, all but one of the regular participants came. The quiet in the room underlined the emotional response to it being the last group. The length of the final session seemed insufficient to accommodate the outpouring of caring for each other, appreciation for the co-leaders, and the expression of how significant an impact the group experience had been on their lives. In both the first group, which concluded with two members and the second group with six members at the conclusion, the last session was a rich experience. The co-therapists in the final group sustained the participants' acceptance of endings in life. Their manner of guiding the participants through their good-byes created a meaningful ending from which they could choose how to say good-bye to their family member. The sense of wonder at the passage of time and the fullness of their learning experiences was expressed in a mood of celebration mixed with sadness.

Given the brevity of the social work group intervention, the participants' expression of not being ready for the end of the group was used as a metaphor for not being ready for their loved one's death either. The group members stated that they "didn't know what to say", "words weren't enough", and, that they "didn't want it to end". The co-leaders ably used these expressions to normalize the experience of death within a family and drew parallels between the group ending and their eventual good-bye to their loved ones. The paradox was shown between

thinking they were ready for the group to end and when the time came, a sense of it being too soon and their not being ready. The co-facilitators expressed their confidence in the participants' ability to extend themselves to each other in the group the best way they knew how, another opportunity to draw a parallel to support the family caregivers' efforts to express themselves with their loved ones at home. Saying good-bye in the group to people who were strangers five weeks earlier represented a microscopic action compared to what they needed to do in their family life with their loved one.

The group participants reluctantly accepted this final stage. They knew when it was planned to occur and prepared for it. Some of them prepared for it by baking or making a small gift. As well, the group members made every effort to attend on time which all that attended did. One participant did not attend the last group and it caused sadness for the other group members. However, the fact that there was an activity sheet to write messages to him and assurances from the practicum student that she would deliver it and the gifts, offered some comfort to them.

### Useful Interventions

As with any learning opportunity, various therapeutic moments become significant and worthy of some comment. The following examples are recognized as being such moments of distinction along the practicum learning process.

Caring reminders. The first experience of the family caregivers' anticipatory grief was their need for reminders to attend the support group. The amount of information and details of their daily lives influenced their ability to deal with additional details (Rando, 2001). When the practicum pre-group interview was planned and the meeting occurred, some people asked for a reminder telephone call and other people did not. When the telephone calls were offered the various individuals expressed a great sense of appreciation for the supportive reminder. Their level of confusion, emotional roller coaster, and anticipatory grief process required a reminder to facilitate their arriving to the group.

The social work position of encouraging client self-determination is often clouded by emotional situations, which inhibit an adult's response. Given the level of emotional intensity with anticipatory grief, it is essential for social workers when they plan an intervention, to nurture the family caregiver even before the intervention begins with this client population. It became clear that the family caregivers were sincerely interested in these groups and yet they had difficulty in arranging respite to attend it, remembering what day the group met on, and to arrive on time for the group. In other social work intervention, these occurrences might be construed as actions of resistance (Rutan & Stone, 2001; Toseland & Rivas, 1998). However, as noted in the literature review regarding anticipatory grief, family caregivers are overwhelmed in this time of their lives and require caring intervention in a myriad of ways, including simple telephone reminders.

Catharsis. The initial session for both groups stimulated a catharsis of pent-up emotion. Certainly in any initial group, the level of politeness is typically

quite high and yet the immediate connections between these group members were evident. In the member to member comments, the warm laughter, clarity of revealing comments in their introductions and the sense of unity regarding the commonness of being forgetful, and on a roller coaster of hope and despair, concretely established the universality of the group. The noticeable amount of tears shed in each first session underlined the significant impact of the intervention and their relief in being together. The participants took care of each other by passing the box of tissues, allowing time for composure to continue speaking and by their supportive comments to one another.

At no other time was there such a significant amount of collective crying. Individuals had moments of tears to express their feelings of despair in future groups but in no subsequent session did the majority of members cry. The sense of universality was confirmed in their sense of relief and felt understanding in being together with other family caregivers. The co-leaders certainly recognized the warmth and level of comfort in these sessions and also underscored the fact that everyone experiences this time in their lives in different ways. The co-facilitators acknowledged that there are different ways to grieve, a “unique point of view”, which are all acceptable to be expressed in the group. They also affirmed the strength of their leadership to “help them along the way” in the group.

Finding a voice. The family caregivers who participated in the group also found common ground in their experiences within the medical system. There was a fair amount of group cohesion in reference to the doctors’ decision-making process, which left the family caregivers feeling outside the loop of information. There was a



sense of being denied their “voices” in the matter of care for their loved one. The opportunity to discuss the doctors’ approaches in a group gave the family caregivers an experience of empowerment, which normalized the process and created a common experience of uncertainty within the process of caring for their loved one.

Within the groups, the family caregivers’ level of trust for the medical staff treating their loved one’s illness was explored. It was quite revealing the amount of trust and mistrust they experienced within the process of anticipatory grieving. Depending on their own level of insight to the life-threatening illness of their family member, family caregivers transferred their anger, frustration, fear onto the medical staff and in particular the doctors involved. The co-leaders responded to this situation by using it as an opportunity for expressing these emotions through the use of narrative therapy. The co-leaders explored the family caregivers’ beliefs about the medical system, in combination with personal stories about their effectiveness in managing other past challenges with professional caregivers in particular. From these stories and beliefs the group participants spoke about their need to speak on their loved one’s behalf, to hear the details surrounding their condition and prognosis as a way of showing their love. The co-leaders heard these stories with an interest in how the individual felt and the outcomes of their experience with the professional caregivers. A therapeutic opportunity to intervene with a strength-based perspective created an instance to consider other ways for them to approach the professional caregivers. These options were suggested by the other family caregivers as well as the co-leaders and it developed choices for them to consider when approaching the professional caregiver another time. As well

through these discussions their feelings of powerlessness and guilt were explored about their loved ones' illnesses and uncertain future. The focus on the "here and now" helped them to contain their concerns, channel their emotions appropriately and to find alternative ways to express them.

In addition to individual catharsis, the group members were able to vicariously gain some insight from each other. Indeed, the participants gave stories of their own moments of transference with doctors and expressed a new insight into the challenges of doctors. The ability to choose their behaviour was explored within the context of having a certain amount of control over their actions, to help manage the overwhelming sense of being out of control of their lives. The freedom to express a full range of emotion was celebrated by the whole group in various comments throughout the group process. The sense of permission to fully express their emotions was appreciated within the fuller context of their lives. They revealed many stories of people in their families who "just do not get it" about the life-threatening situation of their family members. The family caregivers indicated many situations where other people have told them how they "should feel or act". They repeatedly expressed their appreciation for the place to have their authentic feelings revealed, heard, validated and supported within this circle of other family caregivers. The process of gaining their voice within the support group, through telling their stories, empowered them within their family and other areas of life as was revealed in the group discussions.

Session opening. These weekly times of reflection on the group members' week as a check-in was another opportunity to give voice to their needs and feelings.

The co-leaders soon became aware of the fact that the family caregivers' sense of self revolved around the wellbeing of their loved ones. The family caregiver was so used to reporting on the condition of the person with the life-threatening illness, that they did not know how to respond about their own condition. A typical response of a family caregiver was "I am fine. What do I have to complain about? I am not sick or dying." Gradually their sense of appreciation for the check-in was so great that they would begin to do it with each other before the co-leaders began the group. Initially the questions revolved around how the ill person's week had been and then there were inquiries about how did the caregiver take care of him/herself. For some group members these questions allowed them moments of leadership to inspire other caregivers about what to do to sustain the long journey of loving someone in the final stage of living. While other group members encountered this time as a moment of recognition for changes made within their week, affirming their learning from the group experience.

The strength-based position of narrative therapy supported this process of joining group members in a caring process toward empowerment. Epson and White (1990) promote the strengthening of individuals toward changing systems in society. The family caregivers' perspective on what they were able to change was focused on the current situation, their behaviour and, the needs of their family member with a life-threatening illness. There is the possibility that the effects of this group experience and the process of anticipatory grieving will have an impact within their family, support circle of friends and the community. The mandate of this practicum group was to promote an internal process of change, which would

have immediate ramifications within their family and experiences of the medical system. The combination of experiential activities to provide insight and develop changes, which were supported within a group with a narrative therapeutic stance, facilitated the increased amount of self-care and sense of strength in the family caregivers.

Homework. The goal of facilitating emotional expression in the group intervention through experiential activities was met within the check-in process and it set the tone for the session to come (McCallum et al., 1993; Nichols & Schwartz, 1998). Although the activities were referred to as “considerations”, the participants always called them homework. This generated jokes, people teasing one another and the co-leaders about “getting into trouble” if they were not completed, having to stay in after the group as punishment or being a “teacher’s pet”. The sense of humour in the groups was quite fully expressed, especially noted in the second group. It was used as a means to relieve emotionally tense moments, to connect with each other and the co-leaders. The conversations facilitated by the co-leaders within the group context also supported their choices to spend time with the activities or to put them away for another time. The co-leaders offered support for their choices within the narrative therapeutic, strength-based position, which gave each participant the freedom to discern their actions based on their frame of reference, and honoured their self-determination (Bohart & Tallman, 1998; Walsh, 1998; White & Epston, 1990).

When the participants presented their activity sheets there was a strong expression of awareness of options for taking actions in a different direction to

relieve their stress levels, to nurture their relationships and to find balance in their lives. The co-leaders took the opportunity to normalize the freedom to choose what is best for them individually and the fullness of possibilities in their responses. In both groups there were participants who balked at the suggestion that they spend time with the paper activity however they all reported time spent in thoughtful consideration of the task.

One of the paper considerations was the task of filling in their “handful of responsibility” on an outline of a hand. Some of the participants wrote out every detail of their responsibility for the management of their home, family activities and, their loved one’s care. Other people drew the details of their responsibility or coloured the hand in a specific manner. The level of catharsis achieved during this activity was significant in that it was a visual representation of what was causing them to feel a high level of stress. Their heightened awareness empowered them to make different choices in the future. One woman took the initiative to delegate home repair work to a hired handyman and to ask her sister-in-law to begin to come to medical appointments and be responsible for the dissemination of information to the rest of the family. She returned to the group with a great sense of relief and celebration for her being able to take control of something in her life.

Another paper consideration was the task of creating a “caregivers’ room” in which their needs would be met. The group participants were advised to spend some time in thought about this possibility and design a room to meet their needs. Again, the same range of responses occurred as noted above. A woman who was in from out of town to care for her loved one completed one notable result of this

consideration. She created a room that met every sensory level of experience. There were books to nurture her thinking, chocolates to respond to her sweet tooth, pictures of her family, windows to look out at nature to be reminded about the bigger picture of life, her Bible to remember to keep her faith in God strong even in moments of weakened spirits, a candle to perfume the air with an aroma to ease her stress, an easy chair for comfortable reading or listening to music, and a bed to lie curled up on to refresh her body. The incredible volume of details, some of which were omitted here, inspired her to create that room to the best of her ability in the home where she was staying. The inspiration from that activity by one participant also affected another group member. She brought in a beautiful scented candle and "home made" fudge to the next session. Then she gave the candle and holder to the other woman to take home.

The many methods of self-care were reflected on by the co-leaders to represent the different ways for relaxing, taking care of themselves and for creating a caring place in their mind. The variety of "rooms" included the kitchen, a hot tub in the winter and sitting on a rock in the woods. They were reinforced as reminders of how to meet their needs in simple ways, either in reality or in their imagination, when their lives become so stressful. These ideas also served as information for consideration when looking at how to connect with their loved ones and to bring them comfort when they are no longer able to eat or respond in conversation.

Empty chairs. The impact of an empty chair has been recognized in group therapy as an opportunity to discuss loss, death, and termination of the group (Piper, McCallum & Azim, 1992). In working with family caregivers of people with

a life-threatening illness, an empty chair has a deep resonance with their current life. These people are already contending with the reality of someone's imminent death, their absence from the family circle, and the empty chair at the next family occasion. Consequently, in the second session of the first group, the occurrence of two empty chairs was quite significant. The co-leaders felt in a quandary about how to proceed with the group. Their initial response was shock and disbelief, similar to any other unexpected experience of death (Kübler-Ross, 1973). Then, they began to discern what would be the most therapeutic process to follow. The co-leaders decided to follow the "here and now" concept of experiential therapy (Nichols & Schwartz, 1998). Their original focus for the second session was the caregiver family history. Since there were two participants who came with stories from their week and about their caregiver family history, the co-leaders decided to begin with them and their issues. The simple explanation about the other members "not being able to make it tonight" was received at face value. Then, when the discussion about their lives moved to a point where there was a natural bridge to create a segue to a fuller explanation for the others' absence, it was taken.

The co-leaders responded to their factual questions with the basic information they had gleaned from the obituary and determined how the group members wished to respond. Then they considered the next round of comments in an interpersonal quest for future reference by the group participants. The group members wanted to know how would these people be cared for in the community and who would help them next. This discussion gave the co-leaders an opportunity to reveal the plan of giving them a resource list, which would also be given to them

at the end of the five-week session. As well, there was an opportunity to invite them to tell some stories about how their families have lived through a previous death and how it was managed. By looking at this information, the co-leaders were able to discover the group members' belief about how they would cope after their loved ones' death.

The narrative therapy stance for the social worker is to reveal the stories, which are the framework for individuals' lives and determine if they fit with the here and now. When there is a discrepancy between their belief system and reality, that is the opportunity to reflect on their choices and determine if the discrepancy gives them an opportunity to "re-author" their lives (Cheung, 1998; Nichols & Schwartz, 1998; White & Epston, 1990).

Learning self-care. A situation occurred with a woman in the first group who recounted a recent story. She told the group about a shopping trip with her loved one and she completely forgot what it was that she was shopping for, and became flustered. The terminally ill loved one looked at the group participant and advised her, "It is okay, we will look after each other." The concept of the one with a life-threatening illness caring for the caregiver was very uncomfortable for the group member. It was an exception to her personal story about how she always cared for this person, even before this illness. The co-leaders were able to use this situation to illuminate the continuation of the reciprocal relationship, the need for balance in someone's story and the opportunity to receive help as an example of their humanness even when they are a family caregiver of someone with a life-threatening illness. This moment in the second session of the first group became



important to the group of family caregivers, and co-leaders, as a recurrent theme and then again in the second group. The issue of who cares for the family caregivers came through within each session. The opportunity that the group represented to the caregivers was solidly known as “my time” and it became quite protected. As much as was possible to do, appointments were rearranged, employment days were rescheduled or adjusted and the other family members were informed not to disturb the participants unless it was absolutely necessary.

The co-leaders felt the intrinsic validation of the group intervention with these stated actions. The family caregivers felt the caring from each other and from the co-leaders. In their quest to care for their loved one with a life-threatening illness, the caregivers came to realize the value and inherent need to care for themselves as well. The goal to find a balance in their life, between their needs and their loved one’s needs, became central in how they responded to their situation. The support group heightened their awareness of their needs, long ignored, and, brought to their attention the choices they had. Many times within the sessions the family caregivers would sit back and be somewhat amazed (often-expressed in surprised laughter) that they had a choice. This piece of enlightenment gave them a sense of freedom and empowerment to direct their days differently as they determined. The ability to make a decision about something gave the family caregiver a sense of control in a situation that often felt out of control to them.

Re-balancing relationships. Another “aha” moment came when the session focused on communication included a discussion about Ira Byock’s five things to say before someone dies (Byock, 1997). The five things Byock advises people to attend

to with their loved one before they die are: I love you; Thank you; Please forgive me; I forgive you; and, Good-bye. These five ideas create a foundation for intimate conversations between people who are nearing the end of their relationship. It was presented as an option within the framework of self-care. Given that the group participants had different relationships (e.g. daughter, mother, husband, wife etc.) and their loved ones were in different stages of illness, the motivation for these intimate conversations to occur varied. Some of them thought that it was premature for part of these conversations to happen and others wondered if it was a sign of giving up hope. As the family caregivers were guided to review some of their stories about the role of a family caregiver within their families, the thought of redirecting their relationships in an effort to help shape their future ones was received quite openly once the process was re-framed with a future. The group participants sought opportunities to be proactive in their situations, "anything to make it better" was another norm for the group, which promoted their empowerment (Toseland & Rivas, 1998; White & Epston, 1990).

Byock's (1997) first two ideas were met in both groups with an "oh ya, I do it all of the time" sort of response. It seemed to be a natural part of their lives to be expressing their love and appreciation to each other. The concept of asking forgiveness and understanding from their loved one was a sobering thought that required more reflection. The need to find reconciliation for any past transgressions brought a tension of insight and awareness. The idea of an on-going relationship, one with an established narrative within the family, was accepted with all of the bruises and scars of a life together. The co-leaders' implicit invitation to continue to

engage in heartfelt conversations with their loved ones felt uncomfortable for some of the group members, who actually expressed their sense of being pushed.

However, within the discussion of active self-care and narrative framework of re-authoring their story, there came a level of acceptance and understanding for their work ahead (Cheung, 1998; White & Epton, 1990).

The strongest reaction from the group members came with the concept of offering to give their loved one forgiveness. Comments such as: "How could I do that?" "There's nothing I need to forgive them for, they're dying after all."

Another complicating emotion of anticipatory grief is one of guilt, sometimes known as survivor's guilt (Piper, McCallum, & Azim, 1992; Rando, 2000). It was a delicate conversation within each group where the co-leaders navigated the mine-field of past and present emotions to assist them with the discovery of what they wanted to do in the here and now. This conversation urged the group members to reflect on any unresolved situations between them and their loved ones. It promoted their emotional honesty within the group to name their needs and feelings, and then begin to express their emotions honestly within their family relationships. The experiential therapy focus of the "here and now" really translated well for the caregivers who are living with someone with a life threatening illness (Nichols & Schwartz, 1998).

From that session, the revelation for the co-leaders centered on the protectiveness of the family caregivers for the one with the terminal illness. In effect some of the caregivers were willing to absolve their loved one of their mistakes and begin to create the illusion of perfection even before their death. It appeared that

this protectiveness was as much for them as well, to keep from opening a mine of buried emotion, which they were uncertain if they would be able to bury again. The opportunity within the group to express their emotions and gather a response from other group members and the co-leaders gave the individuals a newfound confidence in their ability to speak about their feelings and receive validation for them before they decided what to do with their loved one.

This awareness was sometimes translated into their family relationships. There were people in both groups who mentioned that they spoke with their loved one about some issue between them or the group member changed his/her behaviour with his/her family member. One member told the first group that she had made plans to join a fitness program in October. As much as she was committed to her loved one's care she had come to realize from the discussions in the group, that she needed time for herself and to make plans for her future. Another person in the second group realized that her worry about the future was having an impact on her present time. This woman was in Winnipeg to care for her elderly parent. The larger family dynamics were such that no one in the Winnipeg area had been visiting this dying person and the group member thought it was time. Through the group discussion she had come to realize that her need was to invite them to the home to visit. She also came to realize that she could not force someone to come, and by giving the other family members the invitation it would open up their ability to make a different choice than what had been occurring. The outcome of this story was many visits by family and friends in the final three weeks of her parent's life. The mother was not aware of the visits but they nurtured the group

member's spirit. She was so thankful and felt such a sense of relief that her presence in the group was joyful and not heavily burdened.

Another group member became aware of some anger at her ill parent and the family narrative, which had been so indoctrinated into her being. The family mantra had always been from her mother's perspective of "everything will be fine", a very right or wrong world with no gray areas or room for individual responses. She sat in the group with the new knowledge of a diagnosis of a brain tumour in her mother's head and her family narrative did not work for her. A particularly poignant session in the second group occurred when she angrily challenged one of the co-leaders for her comment about "pain with a purpose". Within the confrontation, the group member swore and questioned the leadership. The situation was effectively responded to by acknowledging the questions, tolerating the outburst and affirming the unique perspective of all group members. The session discussion was out of sync with her stage of grief, one of shock and denial. It was uncertain if this participant would return the following week. However she did return with thanks for the opportunity to fully express her emotions, insight, and an apology for her language. She revealed that one of the family stories she inherited from her mother included the belief that everything needed to be calm and that "everything will be fine". Yet she did not feel calm nor could she be sure if "everything will be fine" and she certainly did not appreciate the doctors or social workers giving her platitudes. In her reflecting on the previous week's outburst, she also gained an insight into how the doctor might feel in his work with people with life threatening illness. This revelation promoted her ability to reframe her

responses to the doctor and reconsider her approach to him for the next meeting. Her appreciation extended to the group for their acceptance of her and the new "family" experience of compassionate understanding in difficult times. The group responded with understanding as expressed through humour and their full attention to her comments.

The effectiveness of the narrative therapeutic stance of the co-leaders was evident in their response to this group member's confrontation. With their professional positive regard for her, the acceptance of emotional expression and the willingness to discover the exception to her story, the co-leaders promoted and supported her personal catharsis. The nonhierarchical position validated her struggle with her current life experiences within the context of her family belief system. When she expressed her anger in group, it was a unique experience that broadened her family narrative about being calm even when confronted with difficult situations. The discovery of her ability to choose how to respond as an autonomous person supported her sense of being a capable person. Through this experience she was able to express her anticipatory grief and regain a sense of mastery within the process of meeting the challenges in her life (Cheung, 1998; Eron & Lund, 1996; White & Epston, 1990). Even though this group member felt pushed by the group process her experience within the group was a catalyst for personal growth. Within the group process she was able to re-frame her narrative, changing it to include the belief that everything is not always fine or calm, and she can cope. She also expanded her belief in being able to ride the roller coaster of a life-threatening illness with her mother.

These clinically significant events are the highlights of a very rich experience of social work group intervention. The number of insights experienced by the group members and shared between them were inspiring and validated the practicum process. Due to the fact the group members were at different stages of being family caregivers, some had been involved in this role for two years and others only a few days, the wisdom passed between them was priceless and timely. Often group members were seen standing and talking in two's and three's outside the building after the session. After the first session of the second group, in such a group, a person with many months of being a caregiver advised a fresh caregiver "to enjoy every moment". This phrase was reported in the check-in time at the next group and resonated in the group throughout the remaining four weeks. It was said with such gratitude for the gift of insight. A simple phrase coming from one who is living a similar reality affected every member of the group and the co-leaders. These clinically significant events underscore the therapeutic value of social work group intervention for this client population.

### Similarities & Differences Between Groups

#### Similarities Between Groups

In reviewing the two groups, many similarities were revealed and will be discussed here. The common design of the groups as short term social work group intervention meant that the similar advantages and disadvantages of brief intervention were experienced (Rutan & Stone, 2001). They both had rapid

development of cohesion, the experience of learning about how to take care of themselves through this time, and therapeutic supportive factors from the group intervention. The family caregivers also achieved a sense of fulfillment for having completed a commitment when they attended all five sessions. As well both groups ended with a sense of it being premature, that there were still issues to be explored, and a desire to continue meeting to share their experiences (Rutan & Stone, 2001; Toseland & Rivas, 1998).

Another similarity was the female to male, 3:1 ratio. This ratio was anticipated from the literature review (Guberman et al., 1992; Hills, 1998; Miller & Cafasso, 1992; Walsh & McGoldrick, 1991; Yee & Schulz, 2000). These women were partners, sisters and daughters of someone with a terminal illness. They indicated a significant sense of commitment to this loved one and did not express an experience of feeling overly burdened (Kinsella, Cooper, Picton, & Murtagh, 2000; Weuve et al., 2000). Together with the men, the universal belief of the two groups' membership was that this situation was a challenging, life changing opportunity and one that they would honour to the best of their ability. Their common desire to be helpful to their loved one prompted them to join these groups even though the majority of them did not have any more than the basic group experience of family, school, and sports.

Once the groups began to meet, their level of burden was quite obvious. Studies about caregiver burden show the amount of burden experienced varies according to certain factors and these were evident in the groups. The factors include gender, age, relationship with care recipient, length of time as a caregiver,



physical environment for caregiving, stage of illness and prospective trajectory (Clair & Fitzpatrick, 1995; Kinsella et al., 2000; Nijboer et al., 2000; Lawton et al., 2000; Weuve et al., 2000; Yee & Schulz, 2000). However, given the fact that the majority of family caregivers in the groups were in long-term relationships, there was a level of acceptance for their role as care providers within their family narratives. Despite this level of acceptance, however, only one of the terminally ill people (an elderly parent) was dying in a natural timely process. The age range was also a factor in the philosophical stance of most of the participants. The youngest two group members were somewhat not prepared for this experience in their lives and were somewhat unprepared for this experience with terminal illness in their family.

The complex needs of these family caregivers reflected the literature review findings of various authors which show how caregiving demands affect the family caregiver's income, physical and emotional health (Rando, 2000; Weuve et al., 2000). The majority of the family caregivers had been giving full-time care for just more than a year and their loved one was not in the palliative care stage. Consequently the "roller coaster ride" of doctor appointments and discussions about treatment options was a shared experience by the majority of group members. This similarity also created a strong commitment of support to each other to find out how their "ride" went for the week. The high level of the family caregivers' need to share these experiences with each other represented their wish to break out from their isolation of coping with dying.

Given the unique experience of September 11, 2001, the second group had the experience of feeling “normal” and “in step” with society. When the attacks occurred in New York and Washington, the pervasive sense of community shock and overwhelming grief resonated with how they had been feeling for the past few days or years. The larger sense of loss did not seem to complicate their experience of anticipatory grief, only validated it in a magnified form. The family caregivers actually were able to use the American experience within their families to develop more understanding for their circumstances as they coped with the life threatening illness of their loved one. The suddenness of these deaths in the U.S.A. underlined the importance of resolving issues between them and their loved one due to the fact that death comes unexpectedly even within the framework of terminal illness.

The experience of the “empty chair” within the support group process was quite well accepted within both groups (Piper, McCallum & Azim, 1992). In view of the focus for the social work group intervention, it was an anticipated reality for everyone in the group to experience an “empty chair” within their family. Consequently the universality of this expected experience meant that the two groups’ norm for the other group members’ lateness or absence, due to illness or an unavoidable appointment, was well-received as an ordinary part of life. This ability to be flexible and offer understanding to each other was rooted in their experience of the unpredictable nature of the “roller coaster ride” of terminal illness (Roach & Nieto, 1997). This acceptance was also evident in their group policy for allowing cellular telephones to remain on in order to respond within their “on-call” role of family caregiver. The family caregivers indicated that this sense of being “on-call”

was part of their caregiver culture and it was evident in the hallways of the hospital units or doctor's waiting rooms. These family caregivers came with this culture to the support groups and these supportive attributes of respect and understanding became the foundation for both of the practicum groups.

### Differences Between Groups

The viability of the groups was a significant difference. The first group was in the initial formation stage with the original group of four people and then it became significantly challenged by the withdrawal of two people due to a death. The remaining two members were compatible and yet the group had significant limitations due to the membership. The contrast was sharply recognized once the second group began. The sessions were more richly filled with discussions and the exchange of ideas and experiences.

The second group also had a core number of participants who were of similar ages with one member a little older and another a little younger. This common stage of life gave the second group a sense of a deeper cohesion since their similar length of life included longer relationships with their partners, previous experiences with death and an agreement about the injustice of a life-threatening illness coming into their life at this time. However the differences in their life experiences challenged their cohesion. The differences were quite pervasive. One woman was married and the other had never been married. One group member was a mother and the other had never been one. One was a retired professional and the

other member was in the prime of her working life. These gaps in experiences within the first group were bridged by the fact that these two women were dealing with very untimely deaths for their loved ones and they both had large family of origins who had left the responsibility for being caregivers to them.

By virtue of the fact that the second group was bigger, the length of time seemed to be inadequate for each session whereas in the first group it sometimes seemed too long. It could be argued that the first group benefited from being in the intense therapeutic focus of two social workers and yet the limitations of a group the size of the first group are pronounced when compared to the second group. In the first group the co-leaders were required to be very active, while in the second group their leadership was primarily directed to guiding the discussion within the topic for that session. The comfort level with silent moments was also noticeably different between the groups. In the first group the silent moments were not allowed to resonate between the members whereas there was great comfort with the silences. These differences in tolerating silence may be partly due to Group I being the first group for the co-leaders to be working together, the size of the group and the significant differences between the members.

## Chapter Four

### Evaluation

The practicum and the student were evaluated with various methods. The following chapter presents the results of these evaluations. There was feedback from the group participants in their responses to a survey and in their notes from the final session experiential activity. This section also describes a self-evaluation, feedback from the co-leader and comments from the clinical referral sources about the practicum experience.

#### Survey and Impact Statements from Group Participants

##### Client Satisfaction & Perceptions of Helpfulness

At the end of the five weeks, participants were asked to give feedback in a satisfaction survey. This survey included questions regarding the impact of the group on their understanding of being a family caregiver, stress, communication skills, grieving, and whether or not they would recommend the group to other family caregivers (see Appendix H for more details). A total of nine questions were asked. There were six questions with a Likert scale for quick responses, from a rating of “a great deal” to “none at all” and three short answers, open-ended questions to give the group participants an opportunity to describe their experience more fully.

This information was reviewed and comparisons of the groups’ responses were examined. This feedback will be shared with the agencies involved and will be

included in the discussion section of this practicum report with my evaluation and review of learning goals.

Survey results. The Client Satisfaction Survey (Appendix H) was handed out in the last session of each group experience and a total of seven surveys were returned. In the second group, one person did not have time to complete the survey in the session and the other person was not there but had attended the other four sessions. These two people were given the option of completing the survey at a later time and sending it in by mail. One person was able to follow through three months after the group and after the death of his loved one. The other person is still very involved with caregiving and has not been able to follow through with the plan. The overall response to the group experience was quite positive with a consistent expression of support for further groups of this nature. The low number of participants limited the first group and this factor was the only negative comment received between the two groups.

The Likert scale results had a numerical rating for the range of responses, from one for an answer of "Much Better" to five for "Much Worse". To evaluate the practicum, the survey scores were added together for each question. The numerical range for seven survey responses was seven to thirty-five. In the following discussion the total value and a mean score will be noted for each question using a response with the scale.

In response to the first question, "Compared to five weeks ago, I have a better understanding about being a family caregiver", most of the participants responded with a positive indication that their understanding had improved since

they began the group or it had affirmed their level of knowledge. The total score was eleven with a mean score of 1.6. As for their understanding about stress, the statement asked "The group has given me a better understanding about my stress level and what I can do to relieve it.", most people benefited from the experience and had a clearer understanding about how to take care of themselves and to practice more self-care to relieve their stress. The total score was twelve with a mean of 1.7. The ideas about how to improve their communication skills and to respond in different manners to professional caregivers and family members alike were seen as being very valuable. One participant commented about this third session wrote, "especially that discussion on balancing truth with just being there for my mom and how to deal with doctors." Another person commented that "I would not have thought about these ideas for changes if I did not attend the group. I have so much on my mind. I do not usually sit still this long to think." In response to the third question, "The group has given me a better understanding of communication styles and how I can communicate differently.", their responses varied more about how much they learned about grief and grieving. The total score was thirteen with a mean score of 1.8. For some participants "Cancer Caregivers: Here & Now" opened their understanding to the fullness of the experience and they were able to develop more of a tolerance and perspective on the variety of ways in which people grieve. For the others it was a confirmation about what their life experiences have already taught them. Their responses to question four reflected this range. The statement was, "The group has given me a better understanding of grief." A total score of thirteen was calculated with a mean score of 1.8.

The concept of needing to touch their loved one throughout their illness was a new focus for some of the participants. The statement was "The group has given me a better understanding of the need to touch someone with terminal illness." The total score was 9.5 with six people responding and one person giving two answers. Consequently the mean score was 1.5 for six survey results. This fresh awareness of someone's need to be touched within this process of living until their last breath was captured in their survey responses which indicated an improved level of understanding. There was an indication that this concept empowered them in some way to be able to do something for their loved one to bring them comfort. A group member commented that "every night I make sure to go into my mother's room and pat her shoulder or rub her cheek to say good night now because I do not know if she will be there in the morning. It is something I can do." The simplicity of touching was a surprising element of personal growth, which actually had a mutual benefit for loved one and family caregiver alike.

Most of the participants indicated that they would confidently recommend "Cancer Caregivers: Here & Now" to other family caregivers. "Absolutely" was written boldly on two surveys. The total score was ten with a mean score of 1.4. The only neutral response was from an individual who was quite affected by the limited number of people in the first group. Otherwise the group concept was well received and would be promoted by those who experienced it. Indeed their consistent attendance at the groups was another confirmation of their acceptance of the social work intervention as a valuable use of their time when it was at such a premium.



A selection of survey written responses is found in Appendix I which reveal the comments from the group participants. In their own words the group members expressed what they liked or did not like about the sessions as well as what they would recommend for the future. As well as these comments, impact statements from the participants are found in Appendix J. These statements were received by the practicum student from the final activity sheet on the last day of each group. The sheet had a picture with two hands clasped together and the activity was for the group members and co-leaders to write notes to each other as a method for saying good-bye. They provided a heartfelt summary of the group experience from the members as well as feedback for the practicum student.

## Student Evaluation

### Self-Evaluation

Group leadership. Through the use of weekly supervision with my practicum advisor, feedback from my co-leader, client satisfaction survey, and review of the audiotapes, a full evaluation was achieved. The on-going process of discovering the level of learning was invigorating and enlightening for the practicum student. The following section discusses the insights and learning opportunities experienced during this practicum based on the learning goals and objectives.

1. To develop skills as a social worker providing group intervention.

The primary goal was to further develop therapeutic skills as a group facilitator. Going through the process of this practicum was a unique opportunity

to reflect on what part of my therapeutic style is functioning well and what methods need attention and fine tuning. The narrative stance was a productive and comfortable position to be in, in a brief group social work intervention. It felt really respectful to be asking questions based in a genuine position of "not knowing". There was recognition of it being a beginning relationship with the practicum student and each participant in the group. The nurturing connection was generated through the use of focused questions and empathetic responses.

Included in the first goal for my practicum was the hope to develop my skills as a social worker leading groups were these specific skills: to improve the ability to structure a therapeutic group within a specific focus; to skillfully facilitate group dynamics to focus on the here and now; and, to improve my ability to sensitively communicate reflections and interventions with the group members. The sensitive nature of this work necessitated a high level of therapeutic skills and an ability to be separate from the group members.

In the first group, the combination of being anxious to do well in my practicum and the ultra small number of participants meant that the process was minutely managed. There were some times silence occurred and it became obvious that my questions became a filler to promote more thought and guidance for discussion and a method of managing my anxiety. Then, when a death occurred and two participants withdrew from the first group, my anxiety increased. Once that situation was resolved and the group continued my level of anxiety decreased and the amount of anxious questioning became minimal. It became obvious in the

second group that my confidence and comfort level had increased significantly as indicated by the moderate and focused use of questions.

I was aware that I needed to constantly assess and re-assess the process to determine the level of therapeutic intervention. This skill was consistent throughout the practicum. I was able to be flexible and adjust the planned process in consultation with my co-leader and advisor in a number of situations represented some sensitivity to the group intervention and a certain level of skill development. I was able to blend some acquired knowledge and intent for the groups, with an empathetic on-going assessment of what would be of benefit to the participants. When confronted with a significant event in group one, I was able to detach my needs for the group to occur from those of the group participants'. It was most evident in how I provided the first group with the option to continue or not when the two other members needed to withdraw. My primary concern was focused on what was best for the group members.

This concerned stance was also evident when I realized that there was considerably too much planned for each session and that it would not be therapeutically minded to proceed with the plan. Therefore I adjusted the design of the practicum, in consultation with my advisor and co-leader, to have some of the experiential components transferred into homework which were given to the participants for between-group reflection. Taking this initiative guided the practicum process into a very group participant focused position that allowed for more meaningful discussion and heartfelt sharing of experiences between group members. In adjusting the practicum plan, I was still able to achieve my goals for

providing social work intervention to relieve some of the caregivers' challenges. The adjustments facilitated the exchange of ideas and information between family caregivers, diminished their sense of isolation, and encouraged confidence in their ability to be involved with their loved one throughout the life-threatening illness.

2. To develop a comfortable level of confidence with the narrative therapeutic approach of intervention within a group context.

The narrative intervention mode fits philosophically into my frame of reference when intervention is with individuals. A conscious effort to use the narrative approach within therapeutic groups had not been similarly achieved nor widely reported in the literature review. Therefore, this practicum experience was an opportunity to develop my skills in this area.

The second goal was achieved in the manner which I phrased my questions and provided a reframe to the group members' family stories. The use of this method offered the participants an opportunity to reflect on their families' belief systems as told through their stories. Comments such as "I never thought of it that way" indicated the therapeutic space for contemplation was successfully achieved and the participants' capacity to review their choices for being a caregiver was broadened. The position of therapeutically wondering created a turning point for the family caregivers to claim their level of care giving for their loved one, as a choice and not an automatic response based in the "shoulds" of a family story.

I posed questions that allowed the group participants to make choices which confirmed their position of being experts in their lives and re-established their sense of being self-directed. I used the narrative style of intervention to empower the

family caregivers at a time when their perception of life was that everything was out of their control. Their weeks were regularly described as being like a roller coaster out of control and that metaphor was a theme, which came from the group members. I used that metaphor throughout the sessions as part of the story of being a family caregiver and their quest to finding the ability to manage the roller coaster experience by making changes in their narrative. Often during the check-in the group participants would relate how their loved ones' week had been. Their own sense of self was intricately connected to the health status of their loved one. Through the five-week process the effectiveness of the intervention was evident in the changes in the check-in remarks. By the middle of the group experience, the group participants began to include a comment about their loved one's condition and a full description about their own current level of mental and physical health. Even though it was a simple task, the checking-in time with the group promoted an opportunity for each participant to reclaim their sense of self by noticing what they were thinking and how they were feeling at least once a week. As their sense of personal agency increased, the metaphor of the roller coaster decreased, giving recognition to their ability to cope with their unpredictable lives as family caregivers. With these examples the achievement of my second goal was achieved.

3. To explore the experiential approach within a group setting.

This third goal was chosen to focus on the use of an experiential approach within a group setting. Informally I have used experiential intervention within a workshop format. It was therapeutic in eliciting responses, but it was not offered within an established on-going therapeutic group. I had really hoped to use

experiential activities within the group process every session. However it became apparent that these activities took too much time within the group and did not allow for enough focused discussions. The experiential activity sheets as homework functioned quite well and augmented the narrative approach with the increased level of stories coming from the discussion of them. As well the activity sheets created a link between sessions which supported the concept of developing self-care for the family caregivers. I learned that being flexible with the design intent and selective with the use of experiential activities still allowed for this goal to be achieved although somewhat differently than originally intended. Given the fact that most of the group participants were new to the therapeutic group intervention method, body sculptures, role-playing and other experiential activities ought not to be used but saved for participants with some group experience or a longer group intervention plan.

The third goal focused on the skillful integration of the experiential aspects of the intervention in an effort to exact the desired focus for discussion each week. By changing the use and timing of the experiential activities positive benefits and this goal was still achieved. Translating the group activity into "considerations" for home created a connecting thread of thought and reflection between the groups. This change in direction reflected my achievement of the goal of building some insight and ability in this area. By integrating the experiential work as "considerations", I created an opportunity to gain knowledge about the group participant's connection with the group process, their level of stress and, ability to function in a caring manner for their own purpose between group sessions. As well,

the “considerations” became a connection between the previous session and the present one, a method for continuing the discussion and developing it into the focus of the current session.

These experiential activities were also incorporated into their awareness as being moments of self-care. These activities provided an opportunity for them ease into the concept of taking care of themselves by giving them “considerations” from the group. Then each week my co-leader and I supported this work, as much or as little as the family caregiver had time to give to the task. This gentle approach to educating the group participants about the possibility of self-care was effectively included within the discussion of each session. By reinforcing their every effort in a respectful manner, the attention given to these unique actions supported the family caregivers’ efforts to sustain a new story about their lives. I felt satisfied with this gentle intervention method when the participants expressed greater awareness of the simple things they can do to sustain their energy and when they reported actually doing something for their self-care. This sequence of methods for group intervention was a true blend of narrative and experiential therapeutic processes, which achieved my third goal.

The use of the “considerations” as a beginning focus for each session also supported the brief intervention design of the group. By using the “considerations” as a focus, we were able to make a bridge between the previous session and link it into a new discussion for the current session. The pragmatic use of these activities supported my necessarily active leadership role in the brief intervention. It was a reflection of our level of skill, in balancing their active roles within the group

process. The focus on these “considerations” gave the family caregivers an entry point each session to guide them back into thinking about themselves and their needs. With this point of reference the participants could also be actively engaged in the group process without too much anxiety. The group participants often asked “what’s next” at the end of a session thereby cueing the co-leaders with their request for the next “consideration”. This request recognized their view of them as being valuable in the intervention process. Indeed there were comments to the effect that some of them would save the sheets of “considerations” as reminders to take care of themselves and to stay connected in thought with the others in the group.

4. To work with a co-leader in a group setting.

In my previous experiences, I have conducted groups as an individual social worker. Having a co-leader expanded my skill level by having to articulate the planning and development of the therapeutic approach. The challenge of relating to another social worker and establishing a therapeutic alliance within the group process was of significant value in my learning experience. The opportunity to be sensitized to the various issues that related to working conjointly with another social worker was a goal rich in insights and professional development

I experienced some initial anxiety due to not having worked with Ms Minaker, and it was evident in some of the first few sessions of the first group. I was uncertain about her style, skill level with groups and nervous about how well we would work together. With each weekly session being successfully completed and candid discussions post session, the co-leadership relationship evolved into an effective alliance. As the co-leader became more familiar with the intervention plan,



the effectiveness of the two leaders became more evident in their seamless intervention. By the second group, the mutual respect and complimentary styles of the co-leaders became more evident in the group process.

Given that these groups were for my practicum there was an inherent imbalance in the joint venture. The sense of equality in leadership was not achieved due to that imbalance. I struggled with how to achieve my goals and to truly be balanced in the leadership and group development process. There was a conscientious effort to discuss the session plan, consult with Ms Minaker about changes to the format and to review the group after each session. It felt unrealistic to invite her to begin a session in the first group because she did not know as clearly what was intended for that session. Consequently her level of participation was not balanced with mine.

The more balanced level of intervention was apparent in the second group when her knowledge and confidence with the session plans was evident in her more frequent contribution to the discussion. In retrospect I realized that I could have offered Ms Minaker an opportunity to begin or end a session by facilitating the check-in or closing process. However, it did not occur to me at the time. Some responses of the group participants, when they referred to both of the co-leaders or looked to either of us in a balanced manner within each session, indicated their consideration of us as being equals. In addition to these other indicators, there were times when the co-leaders had similar thoughts, which flowed into each other or were shared in completing the other's thought.

Although there was not a completely balanced co-leadership, the learning opportunity was significant. I became quite aware of the need to articulate the plan for the sessions and then to hear suggestions for modification of it. The sense of working together was more evident in the second group once the level of anxiety subsided, as mentioned before. I relaxed and felt supported in the intervention effort by my co-leader. I knew that the stories shared in the session were heard by two social workers and that there was joint responsibility to respond. That comfort level was significant in reducing the potential feelings of being overwhelmed by the family caregivers' stories. Although co-leadership has the possibility to add stress to the social workers involved, in this experience the match provided a balance of perspectives, experiences and added assurance of caring for the family caregivers, which supported the positive aspects of co-leadership. The experience also augmented my belief in co-leadership for groups with an intense focus such as these groups, especially if they have a larger group composition.

The co-leadership relationship felt complementary and respectful. Ms Minaker's previous experiences and current place of employment gave her credibility within the group and a link with the community to augment the practicum's focus and my foundation of knowledge and experience. The differences of experiences between the co-leaders were enough so that their mutual respect created an opportunity to model a healthy relationship between people of different ages and level of skills. How the social workers interacted also created a chance for the group participants to observe professional caregivers in an open process of learning. Their authentic responses and acknowledgement of emotion, e.g. anxiety

within the first session, tears at the final session, provided an example of being comfortable with a wide range of emotion and how to respond to it. The supportive nature of the co-leadership endorsed the family caregivers' efforts to take risks within the group, to gain a new perspective on their beliefs about expressing emotions, and possibly, to adjust their family narrative in light of this experience.

I realized that the sense of ownership for the group and the individual sessions was somewhat relaxed in the second group. In an effort to facilitate the therapeutic process and to allow for the "here and now" focus, I further adjusted the plan. It also gave me an opportunity to be more fully open to Ms Minaker's direction and to respond to the group participants' needs.

I considered the co-leadership relationship as an important dimension to this learning experience, in part due to the character and skills of my co-leader, Ms Minaker and, otherwise as a valuable therapeutic intervention lesson. The complexity of co-leadership provided an example to the group, whether the co-leadership was of same or different genders, to represent how healthy relationships function in a respectful manner, how responsibilities are shared or adjusted based on the requirements of a situation and it augmented the supportive environment of the caregiver support group. Potentially a family caregiver support group is fraught with emotional moments. The availability of two social workers within a group created a secure environment in which these emotional moments were explored and the co-leadership fully responded. The ability to attend to many complex situations within this group was augmented with this co-leadership since it functioned well. This experience developed an improved understanding for the

nuances of co-leadership and the opportunity to experience it successfully was highly valued.

5. To learn directly from family caregivers of people with a life threatening illness about their stresses and needs.

The final specific goal focused on the opportunity to learn directly from family caregivers. Having thoroughly researched the topic of caregiving and anticipatory grief, the prospect of actually working with a group of family caregivers in an intimate manner fulfilled this goal. I was able to augment the process of gaining insights into what it means to be living with anticipatory grief by facilitating these groups and learning what is needed for social work intervention to be effective at this stage of their lives.

The family caregivers that participated in these groups were wonderful examples of caring people in crisis. I learned to not underestimate the commitments of love and what people are willing to do to express it. These people rose out of their own level of comfort to do something to help their loved one. I often felt awed as they talked about putting their life "on hold", being "on call" and searching for anything to help their loved one. I learned about how gentle an approach I needed to use to open up the possibility of caring for him/herself as well as their loved one during this time in their lives. I learned to offer reminders to them with kindness, to show understanding for their confusion and feelings of being overwhelmed by the many details of their lives.

These family caregivers taught me about altruism. Even in their own pain they consistently offered caring comments and suggestions to comfort, phone

numbers and electronic mail addresses to keep in touch through the week, and the soft touch of a hand along the way. In the words of one person, "good communication among perfect strangers." They also taught me about being flexible and accepting. Riding the roller coaster of life as family caregivers, they know what caused them to be late and made choices based in what they believed to be priorities in their lives then trusted the other group members to do the same. When the group policies were established, there was evidence of this high level of acceptance in their understanding the need to have cellular telephones on during the sessions and their willingness to welcome group members even if they needed to come late. Their gentleness with each other provided me with an opportunity to learn from them as well, to shape my method of intervention.

A curious situation occurred in the last session of the second group, one of the group members brought her partner to join in. She explained that he traveled a lot, loved her daughter very much and could not attend the other sessions. She requested that he be allowed to join in on the last group discussion. Confronted with this request I had to decide what would be the most therapeutic decision. There were several factors to consider other group members, time and the group process. I decided not to consult the group members and to explain to the participant and her partner that he could not join into the group. The decision was based on the fact that the group was intended to be a closed group and that his presence would change the group's dynamics. In deciding not to ask the other participants their opinions, I guarded the anticipated meaningfulness of the last session for them as well as relieved them of a difficult decision. In doing so I

realized that I stepped outside the realm of narrative therapy and made a unique decision. The outcome of the session confirmed the validity of my choice and I received understanding from the group member and support from my co-leader.

### Evaluation from Co-leader

The co-leader provided weekly feedback in conversation with the practicum student at the end of the session. During those times, Ms Minaker reflected on how the group leadership flowed and the sense of competence in successfully maintaining the focus of each group. She was quite supportive of the practicum student's intervention style, level of emotional reflection and the use of experiential activities. Ms Minaker was able to point out the differences between the first group and second one about level of anxiety, the fullness of silence and the student's ability to weave the focus into the discussions. In all these verbal exchanges were positive and for the final report the student requested Ms Minaker to respond to some questions in writing. The questions and her answers are the following:

1. How would you describe me as a co-leader? How did I communicate with you about the group process and expectations?

“Ruth, I think that you are a great co-leader! You were very respectful of me as a co-facilitator and encouraged me to participate and be active in the role of a co-leader. Other factors have influenced our relationship as leaders, which I tried to outline below.

You were very prepared and clear about the purpose of the group and the goals you envisioned and planned for it. Throughout the process you continued to communicate with me about the changes you saw take place, the excitement it stirred up in you and it confirmed our beliefs/knowledge and/or how it challenged them. You shared your knowledge and lessons learned throughout the process.”

2. How balanced was the co-leadership for you?

“I must admit that at times I did not get a sense of a full partnership in the role as a co-facilitator. I think the reason for that is not simple. I will try to cover them all.

The fact that you are the founder of the group...you came up with the idea, you brought it to fruition. Simply, it is your “baby”.

Group participants’ perception. Some people actually thought that I was a student, perhaps it was our age difference that coloured their perceptions.

My perception of the co-leadership. It was your project and I was helping you, the knowledge that you held the ownership of the group definitely influenced me (just as it did the perception of the group). I wanted to respect your ideas and visions of the group and I followed (versus leading, rather than co-leading). Please remember that these are not feelings you imposed onto me, but that were mine independently.

Practicum student. I think you tried very hard to include me and make me as much of an equal partner as you could. But because of all the above, I do not think it was truly possible. I think our co-leadership would feel and look different if we co-created the group and worked together on it from the beginning.”

3. Did you experience me as being active, passive, flexible, rigid, dominant, emotionally appropriate or inappropriate, nurturing or critical etc.? Please add your own descriptions.

"I think that you have a great sense of balance and you definitely demonstrated that and carried it through in your role as a facilitator. I think what stands out most in my mind is your great ability to be flexible to adjust to the unexpected, surprising situations within the group and really making the best of it. I think you were a great example to the group in terms of your flexibility and ability to adapt to change and going with it.

In terms of being active and passive, you were mostly balanced. You knew when to take charge and when to step back and let the process of the group take off. However, there were a few times when I felt that there was little time for silence in the group. I think that the fact that the group was only 1.5 hours, that there was so much you wanted to cover and that the duration of the group was only a handful of weeks."

4. Compare the co-leadership experience between Group I and Group II.

"I think that both of us have learned so much from both groups. The first group did feel different, because it was the very first group, we were nervous, and wanted it to be perfect (or as close to it as possible). Also the group turned out to be much smaller, which gave it a different feel. The first group was a great learning experience and it added to our confidence as facilitators. The first group taught us about flexibility, balance, and to believe in the process of the group. First group was



almost like the foundation of the second one, we were able to build upon it, to grow and further learn.”

### Co-Leadership Changes Between Group I & II

The co-leaders met several times prior to the initial group. The non-practicum leader, Ela Minaker, was given the proposal to review as well as a few resource books to assist with her preparation. Once the practicum leader completed the preliminary, pre-group interviews, she met again with Ms Minaker to review the group process and to introduce the group members to her. In each group Ms Minaker began with a slight disadvantage due to the fact she had not been a part of the pre-group interview process. However she managed this factor with professional ease.

The co-leadership was a successful match. They had complementary skills and knowledge about anticipatory grief and the role of family caregivers. Ms Minaker actually worked at Health Sciences Centre (HSC) where a few of the participants' loved ones were receiving treatment. There were the usual anticipatory moments of anxiety for the co-leaders just before the very first session of the first group and then there was a confident calm. The co-leaders were able to provide a consistent level of supportive intervention throughout the two groups.

There were noticeable changes in co-leadership between the first and second group in three areas; level of participation, initiative, and use of silence. In the first

group the practicum student was more in the leadership role and had a higher level of participation. Her knowledge of the plan for each session and the direction for the practicum was a reflection of it being her endeavour. As well her experience in facilitating groups was substantially different than Ms Minaker's. However, once the co-leadership relationship was established and the first group for the practicum was completed, a more balanced effort for co-leading the sessions was incorporated in Group II. With the confidence of both leaders developing, with the knowledge of the group members and the design of the process, there was a comfortable flow within the group process.

In the second group Ms Minaker was noticeably more active in the initiation of questions within the narrative framework for the group. Her efforts were timely and well received by the practicum social worker. The blended nature of the co-leadership was smoothly accomplished with the group members referring to each leader in a fairly balanced manner. Also the practicum student's anxiety was lower in that she allowed for more silence and space for the co-leader to contribute more to the process. In regard to this silence, the co-leaders' comfort with each other and their ability to sit comfortably while the group participants absorbed the concepts or questions being directed to them, was quite different in the second group experience. It really contributed to the richness of the process and created a more mutual, co-operative endeavour, which was more consistent with the narrative, non-hierarchical framework (White & Epsom, 1990).

### Feedback from the Referring Clinicians

Information from the sources of referrals was not solicited. There were two comments shared with the practicum student about noticeable changes in behaviour in two people, one family caregiver from each group and a response from each main source of referrals. The two social workers independently indicated that these people seemed calmer and more clearly in their role as family caregivers with their loved ones. One of these clinicians indicated a wish to have the group continue to be available as did a palliative care nurse specialist in the Winnipeg Regional Health Authority Home Care program. As well, a doctor who had observed the preliminary presentation at St. Boniface General Hospital has asked for information about the costs associated with providing this group in the future. These responses confirm that although the practicum experience was limited, it did fulfill a need within the palliative care framework of intervention in Winnipeg.

## Chapter Five

### Conclusion

After having thought for the past three years about the needs of caregivers and families of terminally ill people, it was exciting to explore this therapeutic intervention to meet the needs of family caregivers in this manner. It was an exploration of a service gap that was recognized by professional and family caregivers alike. With this focus and a supportive practicum committee and co-leader, the practicum was approached with confidence.

This experience supported the perspectives that brief group social work intervention is an effective manner in which to facilitate the family caregiver's journey through anticipatory grief and into bereavement. The experience has confirmed the usefulness of social work group intervention for family caregivers of people with a life-threatening illness. The process of family caregivers telling their stories within the context of a group of other caregivers was a liberating experience which empowered them in their experience of anticipatory grief for their loved one with a life-threatening illness. Creating a situation through which they could feel it was natural to be on an emotional roller coaster diminished their isolation and normalized the experience of mourning for the lost dreams of their relationship with their loved one. These encounters between the family caregivers guided by the co-leaders augmented the repertoire of behaviour gathered from their respective family narratives. This expanded feeling of having choices meant that the family caregivers achieved a renewed sense of personal agency within their lives when before the

group experience they had felt out of control and uncertain if they could cope with their unknown future.

The many aspects of anticipatory grief that were reviewed in the literature review were apparent in the groups' discussions. The pervasive sense of the family caregivers' lives being on "hold" as their loved ones' life is threatened by illness, was consistent between both groups. The fact that they felt "on-call" for their loved one was a confirmation of their commitment to the relationship and their level of stress. The recognizable struggle between meeting their needs and that of their loved one was a connecting point between all of the group members.

The group members consistently expressed no time for self-care, that they lived their lives as if it was a roller coaster between hope and despair. These examples confirmed the extent to which they were experiencing anticipatory grief. Everything in the family caregivers' life related to their loved ones' health and the management of it. The family caregivers often expressed great tiredness and a sense of being overwhelmed with the details of life. They had already modified their expectations for their relationships and limited them to a basic level of interaction. This element of anticipatory grief was also evident in their limited ability or permission to ask for help from other family members. One man stated, "My wife is going on a journey and I cannot go with her, hurts me so much."

With the knowledge that these groups were time-limited, the group members had a heightened focus on issues of separation and loss, which mirrored their life situation (Piper, McCallum & Azim, 1992; Rutan & Stone, 2001). It also served as an impetus for group involvement and commitment to the process. The family

caregivers' awareness that the groups were to last for only five sessions actually served to reduce the members' anxiety about the experience on which they were embarking because they knew when it would end. Their individual crises heightened their sense of personal agency and complimented the brief nature of the intervention (Rutan & Stone, 2001; Toseland & Rivas, 1998). One member stated that; " Being here is like taking medicine. You know you need to and it hurts to realize that you need it. I'm glad to have been here." The family caregivers' urgency and desire to learn from this experience was also evident when they were attentive to the time to begin, participated actively, and lingered around after the sessions to speak with the co-leaders and each other. This phenomenon was somewhat noticeable in the first group and quite recognizable in the second group. The second group members initiated the exchange of electronic addresses and telephone numbers. The co-leaders supported their connection to each other and it became a comfort to them, that their connection would be on-going at the end of the five weeks even with the termination of the group.

The group experience afforded the family caregivers an opportunity to gather strength from each other, knowledge, and new insights from the co-leaders to assist them in their goal of being the best family caregiver possible to their loved one. The social work group intervention experience augmented and supported their committed relationship to their respective loved ones. It further developed their ability to lead a balanced life within the framework of anticipatory grief by teaching them about the importance of self-care. The expectation for providing support to family caregivers was achieved. It is conceivable that by supporting the family

caregivers' current experience of anticipatory grief and ameliorating some of the emotional experience of it would ultimately assist them with the adjustment and acceptance of the palliative process which would lead into a healthy experience of bereavement (Kissane et al, 1998: Rando, 2000). The ultimate goal of any social work intervention is to have a positive impact on a family system. In this practicum, the student's wish is to have created a therapeutic intervention which created "aftershocks" (Bowen, 1991) into the family narrative, by creating greater comfort and understanding for them to approach the role of being caregivers for the next person with a life-threatening illness in their family.

### Future Recommendations

The practicum experience helped to identify a need for social work group intervention within the system of caring for the families of terminally ill people. The group gave family caregivers basic information about how to care for themselves throughout their experience of anticipatory grief. It recognized their needs and provided a place and time to focus on how to respond to this life-changing event with other people in similar situations.

However the group members indicated that they would benefit from more time in a support group. The co-leaders came to the same conclusion. The long-term nature of being a family caregiver requires on-going support from professional care-givers throughout the illness trajectory of their loved one. Social work group intervention is a cost effective method of providing support to a number of people

with minimum professional caregiver involvement. The benefit of the therapeutic factors of group intervention augment the experience for family caregivers, validating their challenges and providing support through the process of caring for someone with a life-threatening illness (Piper, McCallum & Azim, 1992; Rutan & Stone, 2001).

The practicum design could be useful as the entry point for family caregivers to receive the basics of understanding anticipatory grief, the stresses and challenges in caring for someone with a life-threatening illness, and, the importance of self-care throughout the process. The system of caring for family caregivers could be structured to incorporate the five-week brief social work intervention with an on-going open-ended support group as follow-up. The brief group would develop the family caregiver's understanding about anticipatory grief and self-care strategies to manage it. The on-going group would then be available to the individual for as long as they needed to attend. With the five-week group as a foundation experience, the family caregivers would have a common experience and understanding of how to participate from which to draw for the on-going group. This model would also accommodate the needs of family caregivers through the ups and downs of their loved one's illness. It could be available to them through the illness and be a place to touch base again briefly after the death of their loved one.

The busyness of our modern life-style and the different ages of people being family caregivers require a variety of times for the availability of such a group. The initial five-week group could be offered continuously to accommodate the families of newly diagnoses individuals. The on-going family caregiver support group would be



recommended to occur in the afternoons or early evenings each week and sometimes on weekends.

The blend of these two models, brief and open-ended group intervention would ensure the emotional needs of a family caregiver were recognized and services made available to them when they need them in a flexible way. With the increase in palliative care services in the community, more people will die at home and their families will be isolated. Their opportunity to meet and mingle with other families at a hospital palliative care unit will be reduced, creating a greater sense of being alone with the emotional roller coaster of loving someone through the illness until their last breath.

The use of co-leadership for these groups is highly recommended. The intensity of the group focus and the emotional content of it would be best facilitated by two social workers. With a larger caregiver support group two social workers would provide the best intervention for these people. However, if the group is smaller a single social worker could facilitate it skillfully so long as his/her own self-care is managed well. The emotional intensity requires a consistent level of self-care in the professional caregivers. Also, there would need to be regular supervision in lieu of the opportunity to debrief with a co-leader. The personal self-care of professional caregivers is essential to sustain the supportive intervention for family caregivers.

The experience of using music sparingly worked well with the five-week support group. It introduced the idea of its use within the home or at the hospital for relaxation or creating a comfortable environment. The idea of managing stress

through the use of music was typically general knowledge however it was confirmed within the group and offered as a suggestion to relieve the stress of being a family caregiver. Perhaps music would be used more often with an on-going support group once everyone was comfortable with the purpose of using it.

Giving family caregivers homework was a delicate venture. It is a gentle way to introduce finding time for self-care and it needs to be offered in a manner, which gives great flexibility for the family caregiver to respond. The homework needs to be given in a non-demanding method, as a consideration of something to do for oneself. These experiential activities were invaluable within the group process to develop a discussion focus, connections between group members and a tangible example of the beginnings of self-care.

The length of the group was ninety minutes. It never seemed long enough for some people and yet it was just the right length of time for others. Due to the high demands on a family caregiver, the group needs to be long enough to be meaningful and brief enough to fit into their busy lives. Ninety minutes seemed reasonable as long as the focus was clearly maintained and the participants were able to discuss it fully. The group members often expressed a sense of relief, even rejuvenation by the discussion and connection with each other, as they were leaving the group. It was sometimes referred to as their "lifeline" for times when they felt they were sinking in the confusion of medical terms and emotional dilemmas.

The curative factors of social work group intervention promote healthy relationships in families. Learning about alternative methods of communicating with other people, openly expressing emotions and managing stress in a group lead

by a social worker, creates opportunities to heal families caught up in a traumatic life situation. This chance to review the family narratives, and adjust them in ways that are required to respond to the circumstances in a healthy manner, represents crucial preventative social work intervention. When a family is experiencing stress related to a life-threatening illness, the crisis becomes an opportunity to confirm the strong family values and to adjust the ones that are not currently functioning well. By introducing other options, a social worker can begin assisting family caregivers with the resolution of past wounds in the family and prevent new ones from being created. The opportunity to learn from other family caregivers in a support group augments the information about choices that families make in responding to a life-threatening illness.

This intervention plan responds to an opening in a family system that was created by the crisis of a life-threatening illness. When a social worker can delicately work with someone at this time, navigating carefully through the emotional landmines of a family, he/she can influence the future of this family. By supporting a family caregiver to attempt improvements in their communication methods within their family, the catalyst of change will continue within the whole family system. With these new communication tools and the support of a group, families can cope better with this challenging situation. With this emotional tune-up, the likelihood of a sustained crisis in a family is diminished. Effectively done, these social work led support groups would prevent the aftershocks of death in the family, as Bowen (1991) mentioned in his article, of divorce, affairs, allergy reactions, depression, health issues, outbursts at school and work etc. By creating

opportunities to resolve conflicts in families before someone dies, a social worker can thwart the possibility of a complicated bereavement process.

This intervention empowers families to make choices today, to support the healthy existing family narratives and develop new ones. In doing so, family caregivers create a new pattern within the family which will affect this generation of relationships and the next ones as well. To be empower family caregivers this way changes the crisis into a challenge where they have some choices in how they respond.

Groups such as "Cancer Caregivers: Here and Now" could become a lifeline to people in those circumstances and a means to ameliorate their suffering. By giving family caregivers an opportunity to meet the challenges of a life-threatening illness in a group setting, professional caregivers would have an opportunity to vicariously care for the person who has the illness, and to promote a healthy adjustment in the future bereavement process. This social work intervention would guide families through the feared dying process and create a possibility of it being not so horrible an experience. The hope for a pain free process of living with a life-threatening illness can be managed and achieved with medication and supportive intervention for the individual with the illness. Relief from the painful process of anticipatory grief needs to also be offered to the families in the palliative process. Only when their needs are consistently recognized and social work intervention provided can we change a family's narrative about dying and death. From that point, only then can we move to hope for a society to change from death denying to life affirming and confident to care for someone until their last breath.

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Within the  
Support  
Group  
experience,  
individuals  
will gain  
strength  
from  
sharing  
common life



experiences with others in  
similar situations.

For further information and to  
arrange a pre-group interview  
with the facilitator,  
please call  
before July 20<sup>th</sup> 2001

**Ruth Zetner**  
**Master of Social Work**  
**Practicum Facilitator**

**889-8525**

Supported by  
Hospice &  
Palliative Care  
Manitoba


This group will be lead by two Social  
Workers, one of whom is fulfilling  
requirements for her Masters of Social  
Work degree.

Supervision provided by Faculty of  
Social Work, University of Manitoba.

## **CANCER CAREGIVERS: HERE & NOW**

**SUPPORT GROUP**  
*for*  
*Family Caregivers of a*  
*loved one*  
*with a life threatening*  
*illness.*

**How do you feel?**

*Tired?*  
*Sad?*  
*Panicked?*  
*Fearful?*  
  
*Guilty?*  
*Angry?*  
*Lost?*

*Overwhelmed?*

The challenges, which face  
families at this time, are  
enormous.

Appendix A

This five week Support Group is an opportunity for caregivers.

- to meet other family caregivers
- to increase coping skills
- to share experiences and strategies for helping someone through their illness.

Small group discussion will focus on the common needs and feelings of adult caregivers and how a life threatening illness has affected their lives.

Master of Social Work Practicum  
Supported by  
Hospice & Palliative Care  
Manitoba

*Topics covered in the five week group:*

*Resilience, Self Care & Healing through Caregiving*

*Recognizing & Relieving Stress*

*Building/Bolstering Communication Skills*

*What is Grief in the Here & Now?*

**Each weekly session lasts approximately 90 minutes.**

St. Boniface Hospital  
Education Centre  
Nurses Residence  
431 Tache Avenue, Room 1037  
Wednesdays in August  
4:00 - 5:30 pm or  
7:30 - 9:00 pm

Self-referrals welcomed.

Adults of any age who are involved as caregivers for someone with a life threatening cancer diagnosis are welcome.



Husbands, wives, partners, mothers, fathers, sons, daughters, brothers, sisters, aunts and uncles, grandchildren and friends.

July 2001

Dear

At Hospice & Palliative Care Manitoba we recognize that caring for someone with an illness is a major commitment. You are often in our thoughts and we care how you are doing.

We want to let you know about a resource that might be helpful for people such as yourself who are caring for a special loved one. Ruth Zetner, a Social Worker known to us who is completing her Masters Degree, is offering a support group for family caregivers. For some people a group can be a place to find encouragement, understanding and practical ideas to make it all work. You have the opportunity to join either an afternoon or evening group. Each group will meet once a week for five weeks throughout August. There is no fee for participation. See the enclosed pamphlet for more information.

If you think you might be interested in joining one of these groups or would just like more information, please call us at 889-8525.

Please call us if there is anything we might do to help, or just to tell us how things are for you.

Yours sincerely,

Brenda Hearson, B.N.  
Megan McLeod, M.S.W.  
Program Co-ordinators

Appendix B

**CANCER CAREGIVERS:  
HERE & NOW**

**SUPPORT GROUP  
for  
Family Caregivers of a  
loved one  
with a life threatening illness.**

**Support Group begins**

**Wednesday September 12<sup>th</sup>**

**4:00 - 5:30 pm**

**(five Wednesdays)**

**To register and for more information contact:**

**Ruth Zetner**

Master of Social Work Practicum  
Supported by  
Hospice & Palliative Care  
Manitoba

## Appendix C

### Pre-group Interview Questions

Name: \_\_\_\_\_ Date: \_\_\_\_\_

1. Who are you a caregiver for?  
\_\_\_\_\_
2. How long?  
\_\_\_\_\_
3. Have thee been any other recent losses in the family? E.g. jobs, separations, divorces, children leaving home, moving, etc.  
\_\_\_\_\_
4. What experiences have you had with groups in general? E.g. school, family, teams, etc.  
\_\_\_\_\_
5. What experiences have had in a support group?  
\_\_\_\_\_
6. What has been your role in these groups?  
\_\_\_\_\_
7. Describe the group – 5 weeks, closed group, commitment, similar people with similar concerns.
8. What do you hope to get out of the group?  
\_\_\_\_\_
9. Give person consent form to read and discuss questions, then sign.

## Appendix D

### Practicum Information & Consent Form

#### Title of Practicum: **Cancer Caregivers: Here & Now**

You have indicated a willingness to participate in a social worker led group, which is being offered as part of the requirements of a master of social work practicum.

#### Purpose of Group

The purpose of the group is to offer support to the family caregivers of people with a terminal illness. The group will provide an opportunity to meet other people in similar circumstances, learn about how to care for your loved one and to address your own needs as a family caregiver.

#### Group Process

Participation in a group may be a new experience for you with uncertain benefits. It has been known as a helpful intervention to other people with similar life situations. As a group participant you will be asked to commit to attending five weekly sessions of 90 minutes. The practicum student and a co-facilitator will lead the groups. The group experience will be audiotaped to allow for the practicum advisor to supervise the process. There will be a brief questionnaire given to each participant at the end of the five weeks in an effort to evaluate the experience.

It is possible that talking about your current life experiences caring for a loved one who has a terminal illness may make you feel uncomfortable or sad. The practicum student will respond to you as you experience these emotions as part of the group experience and facilitate the process of resolving them with you. As well, if individual intervention is required a referral back to the primary agency will be offered.

There are no costs to you for participating in this group, other than your time and you will not receive any compensation for your participation in this practicum experience.

### Confidentiality & Voluntary Participation

Written and audio-taped records that contain your identity will be treated as confidential. There will be a practicum report in which your identity will remain confidential. No information revealing any personal information such as your name, detailed information about your personal situation will be made available to anyone other than Hospice & Palliative Care Manitoba.

Your decision to take part in this practicum is completely voluntary. You may refuse to participate or you may withdraw from the group at any time. The practicum student will be responsible for referring you to other resources that would meet your needs.

You are free to ask any questions that you may have about your rights as a participant. If any questions come up during or after the practicum experience, contact the practicum student, Ruth Zetner at 889-8525.

### Consent

1. I have read and understood this Information and Consent Form, and I freely and voluntarily agree to take part in the practicum group.
2. I understand that I am free to withdraw from the group at any time, for any reason.
3. I understand that the practicum advisor will be supervising the student and will be reviewing audiotapes of the sessions as part of the educational experience. I have been

assured that my name, address and telephone number will be kept confidential. By signing this document, I give permission for such review and fulfillment of educational requirements.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Printed name of above: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Printed name of above: \_\_\_\_\_

Practicum Student: Ruth E. Zetner,  
Hospice & Palliative Care Manitoba  
N119-2109 Portage Ave., Winnipeg, Manitoba



## Appendix E

### Planned Intervention Weekly Outline

#### Week One

Focus: Caregiver Stress

Opening. Music will be quietly playing as people gather in the meeting room. Introductions will be formally done when the check in begins. Group members will be asked to give their names and indicate the reasons for coming to the group. After all the participants have introduced him/herself, then group policies will be developed and explained to provide a comfortable place for everyone to participate.

#### Experiential Activity #1 "Handfuls" (Dossick & Shea, 1988)

Instructions. Hand out a photocopy of hands and pens. Ask the group members to write in what are they responsible for as the caregiver, and, for their whole life e.g., job, family, friends, volunteer work etc.

Discussion. How do you feel? e.g. burdened or content, juggling act or balanced? Anything you can let go or not do? Share? The group members will introduce their handfuls and a discussion of similarities will be facilitated to make connections between members. The social workers will wonder about guilt, how it affects their relationship with their loved one, dynamics within the family, previous experience with being a caregiver, etc.

## Experiential Activity #2 Caring for the Caregiver Room

Instructions. Hand out coloured pencils and picture of the room. What would a room look like that would have everything you would need to be cared for and to relieve your stress? Spend a few minutes to think about your response and create a room. Find a partner to discuss your room, taking turns to introduce your room to each other. Reform the group to individually introduce your room to the group. Co-facilitators will encourage the presentations and identify similarities and differences. How do you manage your stress now? Who do you ask for help? Who holds your hand when you are in a stressful time?

Considerations. Until we meet again, think about how you can lighten your load? Who can hold your hand through this time and support you through this time?

Closing. The facilitators will ask for comments and reflections about the evening's group experience. A quiet ending with music filling in the spaces where words are not spoken. After a reasonable amount of time, the group members will be asked to say good-bye to one another in a manner in which they feel most comfortable.

### Intervention Goal Achievement

1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.
  - This goal is achieved when the group members meet and hear other family caregivers' stories. They will gain a sense of community, an increased level of understanding and validation from other family caregivers and social workers.

2. To engender confidence within the family members, to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.

- This goal is reached, when group members are speaking to each other in the group or in pairs. The family caregivers can practice articulating their needs, feelings and concerns. Through supportive listening and validation of their experiences as caregivers, group members will gain confidence to speak clearly within their family or with professional caregivers.

3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.

- Through the discussions within the group, this goal will be attained when family caregivers become aware of their choices about how they can continue to relate to their loved one.

4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people.

- On-going assessment based on comments made by the group members.

## **Week Two**

### **Focus:      Caregiving Family History**

**Opening.** Welcome, listening to music and breathing quietly to facilitate the transition into the group.

**Check-in.** The group process will begin with individuals telling the group how their week passed and whether they had any thoughts left over from last week. Then an introduction to session focus for that evening would be given.

### **Experiential Activity      Visualization - Remembering Childhood Illness Experiences.**

**Instructions.** Distribute two blank pieces of paper, pens and pencils. Instruct the group members to trace their hand, palm up both of the papers.

The facilitator will begin the visualization process with the invitation to find a comfortable position, to take a few deep breaths and begin to ask some questions that will lead the members in their visions. E.g. Think about a time when you were little and you didn't feel well. Who was there to take care of you; what did it feel like; did friends or other family members come over; how long were you sick; who were helping hands; how were they helpful, etc. Then, invite the group members to write words or to create images on their drawings, which occurred to them while in the visualization. Give time to allow for some reflection.

### **Discussion**

**Instructions.** In pairs, discuss the experience of the visualization and exchange information about each other's experience, determine similarities, and differences in the experiences.

Give the group 5-10 minutes to discuss their experience and then invite them to return to the large group to discuss the experiences individually. Some questions for consideration: what was revealed within the pairs; what similarities were there between the pairs; what differences occurred to the observer of the story; who helped the most? Topics to be included in discussion, role models, gender roles, cultural factors, feelings, family beliefs, stress etc.

Further Discussion. The co-leaders would then invite the group members to remember any adult experiences of being unhealthy and requiring some caregiving. The group will be asked to remember their impressions, expectations, similarities and differences to childhood experience, choices etc.

Considerations. The group will be invited to think about their perspective on being a family caregiver today, and in the past. It will be suggested that they think about similarities and differences with what they learned about caregiving. Offer the opportunity to choose to continue to be a caregiver in the family tradition or to consider adjusting it in some manner.

Closing. Invite the group to express their thoughts and reflections about today's group experience. After people have had their moments to speak, turn on the music, allow for a quiet ending and then say good-bye in a customary manner.

## Intervention Goal Achievement

1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.
  - Within the second session, the family caregivers will have an opportunity to discover patterns of caregiving within their family as well as in other families. This awareness will normalize their experience of being a caregiver and bring some understanding of the process.
2. To engender confidence within the family members to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
  - The opportunity to speak in pairs and to be listened to within the pair or group gives the family caregiver the unique opportunity to be the centre of attention. This endeavour builds an individual's confidence to speak their thoughts and trust that they will be listened to respectfully. In that manner, this goal is achieved.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.
  - The social workers will offer observations to the group members, which will bring any discrepancies between actions and words that describe their relationship with their loved one.
4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people.
  - The comments of the group members will be recorded to build up information as to whether groups for caregivers are worthwhile.

## Week Three

### Focus:     **Communication**

Opening. In a similar fashion to the previous two weeks, music will be playing and people will be invited to sit down and quietly listen to their breathing while they wait for the group to begin. Once all of the members have settled into the group room, a check-in about thoughts on last week's group, current feelings, and stress will be done.

### Experiential Activity #1 Body Sculptures

Instructions. Each person is asked to create a body sculpture that would best describe how he or she is feeling that evening. They will be invited to move to a different part of the room to create their sculpture. Everyone is invited to remain in their position and try to look around at the other members. The next part of the activity is for them to introduce themselves by describing their creation. The facilitators will request members to describe their position and what it represents.

### Discussion

Instructions. In the full group, the facilitators will ask for some feedback as to how did you feel being in that posture; what did the group see; what is body language; how do you read it; do you believe what you see; how does it fit with the spoken word?

The discussion will be encouraged around the area of similarities between group member's sculptures, making connections between members' comments and their impressions of the activity.

## Experiential Activity #2 Communication Activity

Instructions. The group members will be asked to pair off and position themselves around the room. Next the social workers will direct them to assume different positions and give them various scenarios. The pairs will take turns responding to the social worker's instructions. E.g. in one scenario the pairs are told to stand two meters apart, and one to say to the other in a low voice, how are you? The respondent can do it in any manner they determine to be appropriate. This exercise and others are given as examples to improve the family caregiver's awareness about the nuances of communication.

### Discussion

Instructions. Regroup and discuss their experiences with these activities. What were their reactions? Which positions felt comfortable? Which manner of speaking created distance or nurtured the connection with their match? What makes for healthy communication? What setting or space/distance are you comfortable with? What does it feel like to be listened to carefully? What does it feel like to be understood? How can you tell? How do you get to the point of being comfortable with communicating your feelings? Who do you feel comfortable talking about your feelings with? Can you talk this way with your loved one?



## **Considerations**

What can you do to improve your style of communication? Who can benefit from this improvement? Who will notice the change? How will it affect you?

Closing. Reflections about the group experience and how it affected them will be brought to the closing time. The music will be turned on and a quiet ending time will be allowed for a few minutes before the group says good-bye to each other.

## **Intervention Goal Achievement**

1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.
  - The opportunity to create a body sculpture and to participate in the communication exercise creates a playful and thoughtful experience. The anticipated laughter and conversation generated from their insights will relieve some of the caregiver's level of burden.
2. To engender confidence within the family members to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
  - Given the chance to try different styles of communication builds an individual's selection and sensitivity about how they present him/herself to their loved one, other family members and to professional caregivers. Trying different methods of communication in a comfortable setting allows for risk-taking and confidence to develop.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.

- By offering the chance to test out new skills of communication on other group members, the family caregivers can decide to then use it in their relationship with their loved one. If they feel comfortable with these changes then their relationship with their loved one can benefit and augment the time that they have left together.

4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people. (as previously stated)

### **Week Four**

#### **Focus: Grief**

Opening. Music and a time to relax before the group begins. The check-in process begins when everyone has arrived. Whoever is ready can begin by telling the group about their week. Then he/she can indicate how they are currently feeling, as well as indicating if they took action with the suggestion given in the considerations from last week.

#### **Experiential Activity Five Favorite Things**

Instructions. Hand out five slips of paper to each person and a pen. Instruct them to write down five favorite things separately on each paper. Next direct them to move to a separate part of the room, taking their paper with them. Group facilitators will move from person to person taking away one of the papers and telling the group member that something has happened to that item e.g. lost, a fire, accident etc. After sitting quietly with their reaction/feelings, invite them to move back into the group to talk about their response.

#### **Discussion**

**Instructions.** The co-leaders will invite the group to reflect on, how they felt? What did the reaction feel like? Have you experienced this feeling before? Do you know these feelings now? Can you recognize them as grief? What is grief? When does it happen? Are you grieving now?

The social workers will facilitate a discussion about the different types of grieving, identify them, and discuss the group member's experiences with them. The discussion will include recognizing the similarities between members, within their families, in their loved one, between men and women.

### **Considerations**

Hand out a work sheet with their hand photocopied with concentric circles superimposed over it. Ask them to think about what friends or family member are in their inner circle and to write them onto the page? Do the same with the outer circles as well. Who knows about your grief? Who do you need to tell?

**Closing.** As in other weeks, time to offer individual reflections about the group experience, to listen to music quietly and an opportunity to practice saying good-bye.

### **Intervention Goal Achievement**

1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.
  - In this session, this goal is achieved by reviewing their experience with grief in the past and helping them to recognize their current state of grief. To heighten their awareness in this manner will offer them insights into some of their feelings and experiences of stress.

2. To engender confidence within the family members to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
  - By coming to terms with their experience of anticipatory grief, the family caregiver will be able to attempt to express what they need to nurture or relieve him/herself in view of the complex nature of their present condition. By choosing to take some action in the direction of self-care, the family caregiver can develop a new level of confidence. In doing so, they can then have more ability to respond to the needs of their loved one.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.
  - The recognition of anticipatory grief can motivate the family caregiver to discuss it with their loved one, reminisce about their life together, and suggest how they will remember them when they're no longer together.
4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people.
  - By noting the changing climate of the group and their comments each week, the social workers will gather information for the evaluation of the group for caregivers.

## Week Five

### Focus:     **Healing Touch & Saying Good-bye**

Opening. As with each previous week, music is played while people are gathering for the group. The check-in begins when the group members have all gathered. The co-leaders invite anyone ready to begin to tell the group about their current feelings, how their week passed and whether they thought about the previous group.

### Experiential Activity     Hand Holding Hand (Dossick & Shea, 1988)

Instructions. Hand out photocopy of holding hands to each person and a pen. Randomly connect them as pairs (draw names from a hat). Next direct them to move to a separate part of the room, taking their paper with them. The group facilitators will ask the pairs to share one thing that they have learned from each other in the course of the five weeks. Music will be playing. The group members will be invited to express their feelings for each other by sitting as closely as is comfortable, to hold or massage each other's hands. Time will be given for each person to give and receive this sharing, before the pairs are changed. After sitting quietly with their last partner, a few moments, allowing for personal thoughts and reactions/feelings to surface, then the social worker will invite them to move back into the group to talk about their response.

### Discussion

The co-leaders will explore the group member's responses with questions such as: How did it feel to be touched? What did the reaction feel like? Have you experienced this feeling before? How did it feel to be touching? Do you know these feelings? Can

you recognize them, as intimacy needs? How often do you need to be touched? When does it happen? Are you able to be intimate with your loved one? How do you define intimacy? How do you create it in different settings? In the hospital? A discussion will be generated from these questions. There will be recognition given for different types of intimacy, identify them, and discuss their experiences with them throughout the illness. The social workers will facilitate a discussion about similarities, making connections between members and develop a list of approaches to creating intimacy in hospital settings.

### **Evaluation**

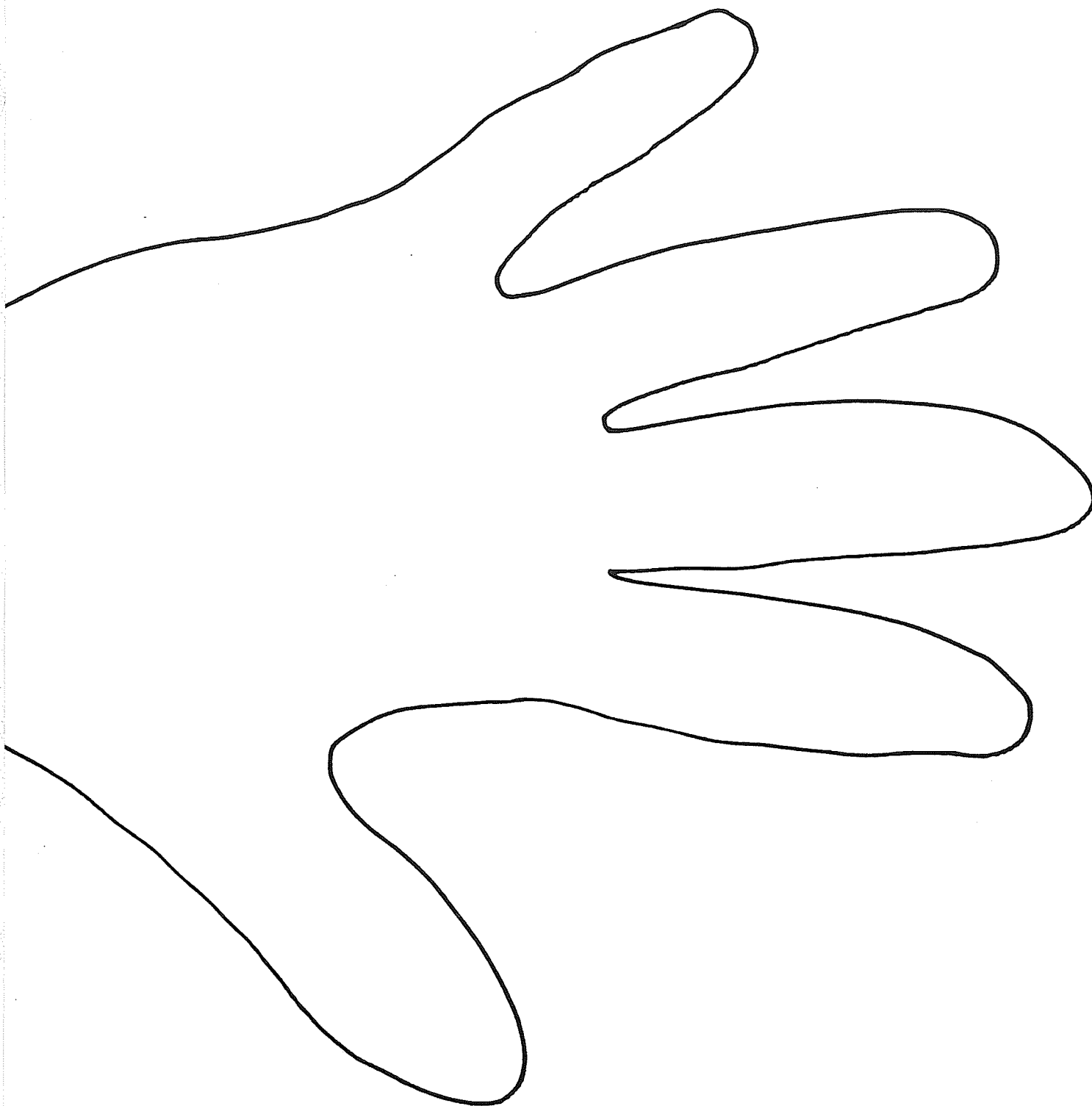
Instructions. The evaluations will be handed out at this time with a request for it to be filled in. The group members will be given enough time to complete it before the closing reflections are offered. In this manner, the task is completed to fulfill the requirements of the practicum with a minimum of interference to the process.

Closing. Reflections about group experience will be offered within the group. Each member will be able to comment on what the experience has meant to him/her as well as what wishes he/she has for the other members. The music will be quietly playing to facilitate any silences or soothe any emotional moments. Then we will say good-bye, as we are comfortable.

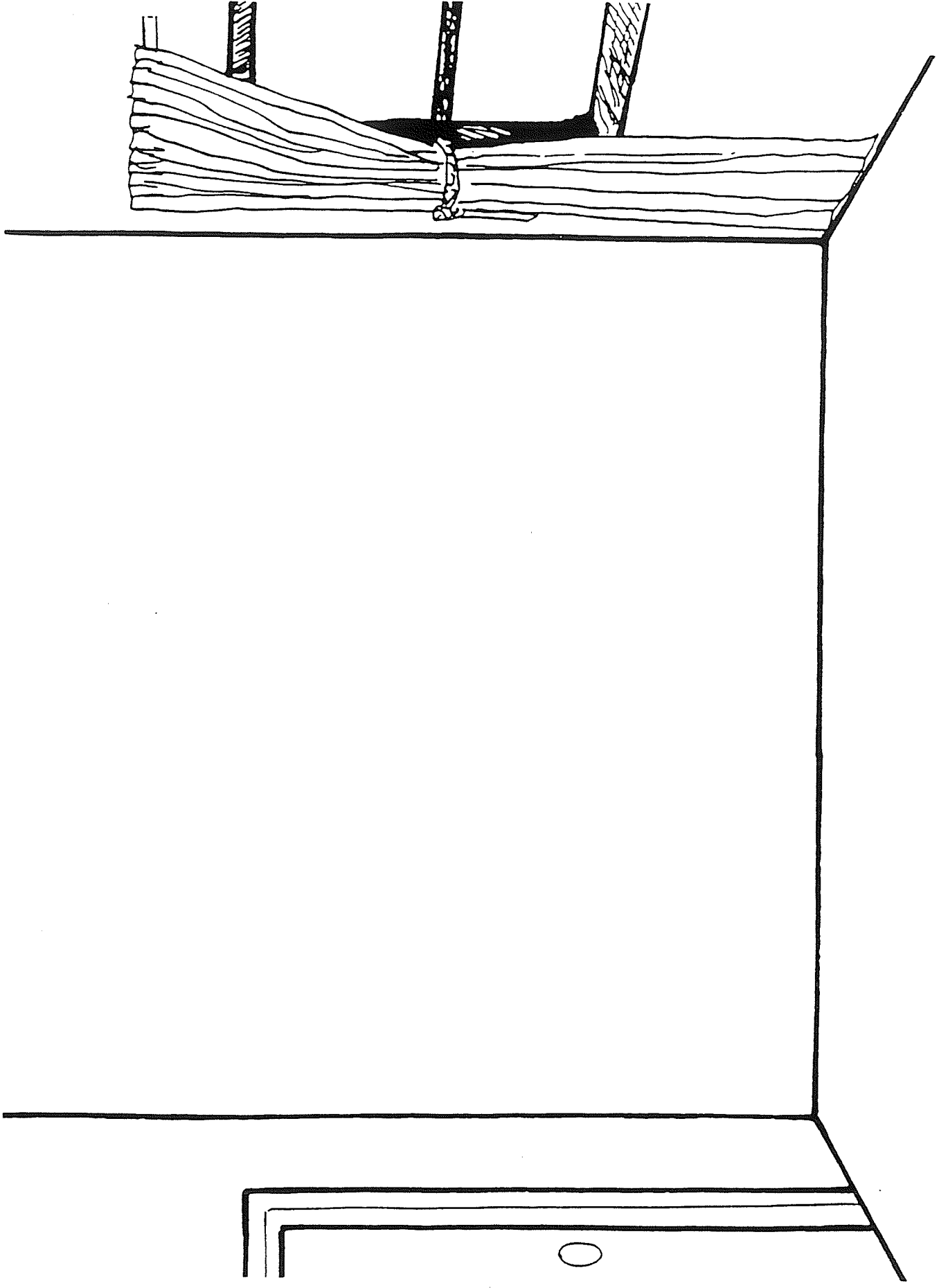
## **Intervention Goal Achievement**

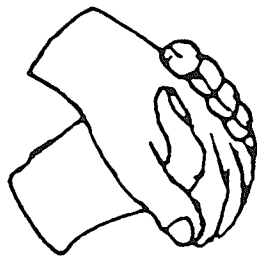
1. To relieve, and normalize, the process of suffering for family caregivers of people with terminal illness, through the provision of multifamily, anticipatory grief groups.
  - By this stage, the group's effectiveness has been affirmed and the family caregiver's isolation has been resolved. Not only has their burden been somewhat relieved but the family caregivers have new skills and awareness of anticipatory grief to prevent adverse reactions to the death of their loved one.
2. To engender confidence within the family members to be able to communicate openly with their loved one and professional health care providers as developed through the group experience of shared knowledge and feelings.
  - This attainment of this goal will be evident by the stories relayed to the group at check-in and throughout the process of the group interaction.
3. To support reasonable expectations for the continuation of their relationship in a characteristic manner within the process of living until death occurs.
  - Having somewhat relieved the caregiver's stress by opening up their understanding about their current situation, the family caregiver can review the choices available to them and relate to their loved one as he/she wants. It is hoped that the options chosen will affirm and sustain the relationship until death occurs.
4. To evaluate the need for anticipatory grief groups and the effectiveness of the intervention in relieving the suffering of family caregivers of terminally ill people.
  - The written and spoken comments will be compiled after the final group and reviewed by the co-facilitators, advisor and community agencies, as to the merits of therapeutic group intervention for family caregiver's of people with a terminal illness.

Appendix F









Appendix G**Available Reading** GRACE GENERAL HOSPITAL: BEREAVEMENT CARE**General Reading on Grief**

- Brooks, Jane. *Midlife Orphan* Berkley, 1999
- Caine, Lynn. *Being a Widow* Bergenfield, NJ: Penguin Publishing, 1988
- Deits, Bob. *Life After Loss* Tucson, Arizona: Fischer Books, Revised Editions, 1992
- Edelman, Hope. *Motherless Daughters, The Legacy of Loss* New York: Dell Publishing 1994
- Fitzgerald, Helen *The Grieving Child, A Parent's Guide* Toronto: Simon & Schuster: 1992
- Ginsburg, Genevieve. *Widow to Widow* Tucson, AZ: Fisher Books 1995
- Grollman, Earl. *Living When a loved One has Died* Boston: Beacon Press 1977
- Grollman, Earl. *What Helped Me When My Loved One Died* Boston: Beacon Press, 1981
- Lewis, C.S. *A Grief Observed* New York, NY: Bantam, 1983
- Hewett, John. *After Suicide* Philadelphia: Westminster Press, 1980
- Manning, Doug. *Don't Take My Grief Away From Me* San Francisco: Harper and Row, 1979
- Moir, Agatha. *Heart's Cry - Diary of a Grief Journey* Available from the Grace Hospital, 2000
- Palmer, E. and Watt, J. *Living and Working with Bereavement, Guide for Widowed Men and Women* Detselig Enterprises Ltd., 1987
- Sittser, Gerald L. *A Grace Disguised* Grand Rapids: Zondervan Publishing House, 1996
- Staudacher, Carol. *Beyond Grief* Oakland, CA: New Harbinger Publisher, 1987
- Staudacher, Carol. *Men and Grief* Oakland, CA: New Harbinger Publisher, 1991
- Tatelbaum, Judy. *The Courage to Grieve* Lippincott and Crowell, 1980
- Temes, Roberta. *Living with an Empty Chair* New York: Irvington Publisher, 1984
- Westberg, Granger. *Good Grief.* Philadelphia: Fortress Press, 1989
- Wolfelt, Alan D. *Understanding Grief* Bristol, PA Accelerated Development, 1992

**Loss of a Child**

- Donnelly, Katherine. *Recovering from the Loss of A Child* New York: Macmillan Pub., 1982
- Grollman, Earl. *Talking about Death: A Dialogue Between Parent and Child* Boston: Beacon Press, 1990
- Schaefer, D. and Lyons, C. *How Do We Tell the Children?* New York: Newmarket Press, 1986
- Schiff, Harriet. *The Bereaved Parent* England: Penguin Books, 1978
- Wolfelt, Alan D. *Helping Children Cope With Grief* Bristol, PA Accelerated Development, 1983

## Books for Children

- Bosak, Susan V. *Something to Remember Me By* Toronto, ON: The Communication Project 1997
- Brown, Laurene Krasny and Brown, Marc. *When Dinosaurs Die* (age 4-8) 1996
- Buchanan Smith, D. *The Taste of Blackberries* (age 9-12) Crowell, New York, 1973
- Buscaglia, Leo. *Fall of Freddie the Leaf* (age 5-10) Thorofare, NJ: C.B. Slack, 1982
- Cohn, Janice. *I Had a Friend Named Peter* (age 5-8) New York: William Morrow and Co., 1987
- de Paola, Tomie. *Nana Upstairs and Nana Downstairs* (age 2-5) New York: Putnam's, 1973
- Ingpen, R. and Bryan M. *Lifetimes* (age 2-5) Toronto: Bantam Books, 1983
- Krementz, Jill *How it Feels When a Parent Dies*(age 7-16) New York: Alfred A. Knopf, Inc., 1981
- Lowry, Lois. *A Summer to Die* (age 9-12) Toronto: Bantam Books, 1977
- Philpot, Don R. *The Moons of Goose Island* Sandy Hook, MB: Hinterland Publishers 1997
- Steickney, Hernadez, & Ortiz *Water Bugs and Dragonflies* Pilgrim Pi. 1997
- Varley, Susan. *Badger's Parting Gifts* (age 6-8) Great Britain: Fontana, 1984
- Viorst, Judith. *The Tenth Good Thing About Barney* (age 6-8) New York: Atheneum, 1971

## Books for Teenagers

- Agee, J. *A Death In the Family* Bantam, 1977
- Craven, Margaret. *I Heard the Owl Call my Name* New York: Doubleday, 1973
- Dower, Laura. *I Will Remember You* Scholastic Incorp. 2001
- Gravelle, & Haskins, *Teenagers Face To Face With Bereavement* Englewood, NJ: 1989
- Le Shan, Eda. *Learning To Say Goodbye When a Child's Parent Dies* Avon Publishing, 1988
- Paterson, K. *Bridge to Terabithia* New York: Camelton Books, 1977

## WORLD WIDE WEB SITES ON GRIEF

- Crisis, Grief and Healing, is a page where people can browse to understand and honour the many different paths to heal strong emotions. <http://www.webhealing.com/>
- Grief Net is a system that can connect you with a variety of resources related to death, dying, bereavement and major emotional and physical losses. <http://www.rivendell.org/>
- A site about grief, how to deal with it, and how to turn it into a positive creative experience. <http://www.growthhouse.org/cgi/search.cgi>

*You may find some of these books helpful.*

*They are available in your local public library or bookstore.*

# Resource and Support Groups

Grief counselling may be a valuable source of support following the death of a loved one. The following agencies provide bereavement counselling and/or support groups:

## ***AGE AND OPPORTUNITY***

Individual and group support for seniors. Bereavement groups for individuals who have recently lost a spouse are scheduled several times a year. The groups are limited in size to promote an informal, caring atmosphere. Registrations is required. **Phone: 956-6440**

## ***CALVARY TEMPLE SUPPORT GROUP***

The program is designed to give people an understanding of the grief process, and the opportunity to share feelings with others in a group environment. Registration is required.

**Phone: 943-4551**

## ***CENTRE YOUVILLE CENTRE***

The Taking Steps Walking Group offers bereavement support in an informal and comfortable way that combines exercise, discussion and companionship. Resources are provided for individual counselling or group support to those having experienced the death of a loved one.

**Phone: 255-4840**

## ***COMPASSIONATE FRIENDS***

Self-help group offering friendship and support to parents grieving the death of a child of any age from any cause.

**Phone: 787-4896**

## ***FORT GARRY WOMEN'S RESOURCE CENTRE GRIEF GROUP***

This is a group for women that will focus on working with the grief that comes from life losses such as death, loss of a relationship, loss of home or job or health. In the eight week sessions we will look at ways of coping with and honouring our grief. Registration is required

**Phone: 477-1123**

## ***GRACE GENERAL HOSPITAL BEREAVEMENT SUPPORT PROGRAMS***

An eight week support group offering a safe, caring environment for individuals who have been bereaved. The program is held three times a year. Registration is required.

**Phone: 837-0560**

A drop-in program is held the first Wednesday of each month to offer ongoing support for bereaved persons. No registration is required.

**Phone: 837-0560**

Individual bereavement telephone support is offered by Grace Volunteers.

**Phone: 837-0560**

## ***GROWING THROUGH LOSS***

This twelve week program, authorized by Jean Monbourquette, is a Christian-based Canadian series of seminars developed for grief support groups.

**Phone: 949-3760**

**HOSPICE & PALLIATIVE CARE MANITOBA**

Offers information on coping with grief and one-to-one bereavement telephone support by trained volunteers.

**Phone: 889-8525**

***INTERFAITH MARRIAGE AND FAMILY INSTITUTE***

Professional counselling services for individuals and families. A fee is charged according to your ability to pay.

**Phone: 786-9251**

***KLINIC - AFTER SUICIDE BEREAVEMENT GROUP***

This group is for adults whose lives have been affected by the suicide of a family member or friend. It is a fourteen session closed therapy/support group.

**Phone: 784-4200**

***NORTH END WOMEN'S CENTRE***

Offers a twelve week grief program for women who have experienced the loss of a loved one.

**Phone: 589-7347**

***ST. BONIFACE GRIEF SUPPORT PROGRAM FOR CHILDREN AND TEENS***

A bereavement support program for children, age 5 to 18, who have lost a parent or close relative through any kind of death, including cancer, suicide, accident or illness. A concurrent group for parents of the children is offered.

**Phone: 237-2344**

***ST. JAMES/ASSINIBOIA SENIOR CENTRE INC.***

Offers a supportive group for seniors who have recently lost a spouse through death.

**Phone: 987-8851**

***STURGEON CREEK UNITED CHURCH GRIEF SUPPORT GROUP***

Support is received by people through sharing of their grief experience.

**Phone: 832-1000**

***WELLNESS INSTITUTE AT SEVEN OAKS GENERAL HOSPITAL***

Taking Steps is an eight-week bereavement walking program for people who have experienced the death of a loved one. Advance registration is required

**Phone: 632-3352**

***WINNIPEG CHRISTIAN COUNSELLING GROUP***

Individual and group counselling are available.

**Phone: 488-1500**

***YM-YWCA GRIEF CONSULTATION CENTRE***

Individual counselling services are available. As well there are bereavement groups for widows under the age of 60 and for children over the age of 18 who have lost a parent, grief discussions for men, and a suicide bereaved support group. There are Y- member and non member fees.

**Phone: 947-3044**

*Sorrows can be borne if you put them in a story  
or tell a story about them.*

*Isak Dinesen*

## Appendix H

### Client Satisfaction Survey

1. Compared to five weeks ago, I have a better understanding about being a family caregiver.

1	2	3	4	5
Much Better	Somewhat Better	About the Same	Somewhat Worse	Much worse

2. The group has given me a better understanding about my stress level and what I can do to relieve it.

1	2	3	4	5
A Great Deal	Better	About the Same	Worse	None at all

3. The group has given me a better understanding of communication styles and how I can communicate differently.

1	2	3	4	5
A Great Deal	Better	About the Same	Worse	None at all

4. The group has given me a better understanding of grief.

1	2	3	4	5
A Great Deal	Better	About the Same	Worse	None at all

5. The group has given me a better understanding of the need to touch someone with terminal illness.

1	2	3	4	5
A Great Deal	Better	About the Same	Worse	None at all

6. After having this group experience, would you recommend it to other family caregivers?

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
With Confidence	Somewhat Confidently	Neutrally	Reluctantly	Not at all

7. What did you like the best about the group experience?

8. What did you like the least about the group experience?

9. Any additional comments?



## Appendix I

### Client Satisfaction Written Survey Results

The following comments are quotes from the short answer survey questions.

#### **“What did you like the best about the group experience?”**

- “The professionalism of Ruth and Ela. Never was I left feeling unguarded or had any questions unanswered.”
- “Being able to share feelings up-front and not be judged.”
- “The openness and honesty of sharing hopes, fears and grief.”
- “Sharing with others in the same situation.”
- “Good communication among perfect strangers.”
- “Your gentleness and acceptance (both Ruth and Ela) and non-judgmental environment.”
- “Everybody, sooner or later, has to accept death - this class is a good cushion.”

#### **“What did you like least about the group?”**

- “We are helping one another in time of sorrow/sadness.”
- “At times I wish our times during sessions was longer, but I do not think I’d recommend making them longer.”
- “N/A - could run longer more than five weeks - on-going? I would continue.”
- “There is nothing negative to say about this experience.”
- “....when I could not make the last meeting.”
- “Not enough people”

- “The introspection was difficult for me at first, but I soon recognized the need to examine my inner thoughts and emotions.”

**“Any additional comments?”**

- “I hope this concept continues and spreads to all palliative centres.”
- “At a later time.”
- “This was an invaluable 5 weeks for me. I wish both you and Ela many, many blessings. You are very special women.”

“An overview would have been helpful up-front...expectations.”

## Appendix J

### Statements of Impact

The following are comments received by the practicum student from the group participants from the last session, on the experiential activity sheet.

- “It will not be easy to summarize all that you have done for me/us in this group. You found the loose strand of thread common in all of us and wove it together leading us in a new path = identifying the similarity of our uniqueness and showing us we are not alone and need not be alone in our life path. Thank you, for your guidance, in a calm energy, leading us to share with no hesitation. I go away knowing I have a new group of friends. Thank you.”
- “Your gentle voice, your guiding hand, your keen perception are so vital in this group. Thank you for keeping us focused on the goal; for allowing us to see the need for balance, for being gentle with ourselves, and, for recognizing and re-enforcing our small strengths, you have helped.”
- “Thank you for all the supports. I wish you well in future endeavours.”
- “I do not usually, cannot sit still. I am glad to be here.”
- “I have not missed a Halloween for years. I am glad I did.”
- “This group has been a blessing - thank you for that. If it ever gets to be a permanent thing I would be interested. I have enjoyed our time and this has been sanity unto itself. I hope to get better at telling those closest to me what I need to.”
- “You make things happen and appreciate your time, hospitality and great learning experience...”

- “Meeting you that day at Moxies was the best thing that happened to me since my return to the “Peg”. Your group concept was excellent, your leadership right on target. I hope this concept will grow and thrive, not just here, but throughout the land. Let us meet for a “bite of brownie” one day.”
- ““What can I say, but Wow!! You created an incredible environment for me to share, to share in ways where I have rarely felt comfortable to do so. I felt pushed a little too hard in one session, but you seemed to respond with patience and wisdom - that I will never forget. These 5 weeks will remain with me and in my heart for always. Thank you so much.”