

**PROVIDING CARE TO A FAMILY MEMBER IN THE  
TERMINAL STAGE OF CANCER:  
FAMILY MEMBERS' NEEDS**

**By**

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**A Thesis Submitted to the Faculty of Graduate Studies  
in Partial Fulfillment of the Requirements for the Degree of  
MASTER OF SOCIAL WORK**

**Faculty of Social Work  
University of Manitoba  
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**Linda Sundevic      ©1998**

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### **Abstract**

A qualitative research study was conducted to identify family caregivers' needs within the context of caring for a family member in the terminal stage of cancer and the caregiving responsibilities family caregivers' perceived as causing stress or burden, then to explore potential gaps in assistance and support for family caregivers. Ten primary family caregivers in a northern Manitoba community participated in the study. Data was collected using an in-depth semi-structured interview with each caregiver. Two main categories of caregiver need were identified: the need for support and the need for information. Emotional support, including comfort, compassion, and acknowledgement of the toil of caregiving, was highlighted. Information on treatments, side effects, symptoms and the progression of the illness was essential to the provision of care. Caregiver stress or burden increased when these needs were not met. Caregivers' satisfaction with the health care system as a whole was based on their interactions with, and the performance of individual nurses, physicians and social workers. The results from this study suggest that the health care system must be more responsive to caregiver needs, especially in the areas of emotional support and information sharing if family members are expected to participate in the caring experience. The development of a health care position dedicated to providing emotional support and information to family caregivers, in which social work interventions would play a key role, is recommended.

## **Acknowledgements**

One can not study the subject of terminal illness without feeling a profound sense of awe at the incredible inner strength and insight family caregivers possess. I am grateful to the participants in this study for their willingness to share their very personal stories with me.

I was extremely fortunate to have advisory committee members who provided guidance with clarity and tolerance. I would like to thank David Gregory and Tuula Heinonen for their time and patience, and endless enthusiasm. Special thanks to Kathy Jenson for countless hours of warm support and direction.

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## **Chapter 1**

### **Introduction**

When a person is diagnosed with cancer, the entire family is affected. Normal routines and roles are altered as the family members move to accommodate the symptoms of illness, the emotional turmoil, and the uncertainty of the future. The family system is altered and each member is affected by the diagnosis, and subsequently, by the development of the disease and treatment process. If the disease progresses to the terminal stage, the very structure of the family is threatened and a state of crisis occurs. At the terminal stage of cancer it is determined that the disease will progress until death occurs. It is during this stage that treatments cease and care is focused on palliation, or comfort measures.

Palliative care is the provision of care to provide comfort and support to a person who is dying and his/her family. The care can be provided in a hospital, a hospice or in the person's home. The health care system provides professional nurses and social workers, paraprofessionals, care attendants and trained volunteers to assist in the care of the dying person.

Wherever the care is provided and whomever provides the care, the family members play an important role. Ultimately, it is the family members - the spouse, the daughter, the son, the daughter-in-law - who are the most important resource for their loved one. The person who is dying may greatly rely on their family members for emotional and physical support.

## **Purpose**

This qualitative research study is designed to examine the needs of family members providing care to another family member in the terminal stage of cancer. I work in the health care field in Thompson, a northern community and region in the province of Manitoba. My experience in the health care field suggests that there is a desire by family members and an expectation on the part of health care providers that family members participate in the care of their loved one. I can also confirm through my experience in the area of palliative care, that family members provide the majority of care when a loved one is dying at home and only seek assistance from health care services when they become overwhelmed with the required tasks and the emotional turmoil of their role. However, the ability of the formal health care system to address the needs of family caregivers and support them in their caregiving role may not be adequate.

Health care providers in the Thompson region, including home care coordinators and hospital-based nurses, have expressed concerns to me that the needs of the family caregivers are not being met in the context of terminal illness. However, no one has defined those specific needs. Efforts to address caregiver needs have been based on casual observations and speculations made by health care providers as to what family members' care needs might be. Although health care providers have some insight into these needs, especially where they are able to identify gaps in the services available, the family caregivers' perceptions of need has not been researched. Since it is the "perceived" needs of the family members that are most relevant, it is important to gather information directly from the family members who have participated in caring for a family member in the

terminal stage of cancer.

There is a desire by the health care system to respond to the needs of the family caregivers and provide the assistance they require to reduce the burden engendered in providing care to a loved one. What is less clear is what the assistance and support should consist of, and how effective it is or might be in reducing the stress of the caregiving experience. Do the expectations placed on family members go beyond their ability, physically and emotionally, to provide the care required? Where do family members obtain their support? What are their care needs? If interventions to support the family caregiving role are to be effective, family care needs must be addressed.

The main objectives of this research study are:

1. to identify family caregiver needs within the context of caring for a family member in the terminal stage of cancer,
2. to identify caregiving responsibilities which family caregivers perceive as causing stress or burden,
3. to explore potential gaps in assistance and support for family caregivers.

The achievement of these objectives will provide a research-based foundation for practise within the health care system. Specifically, to enhance the ability of the health care system to be responsive to the needs of families providing care to a family member in the terminal stage of cancer.

This research study was designed to examine family caregiver needs to determine if the current palliative care services provided through the home care program and other components of the health care system are meeting family caregiver needs. Based on

practice experience, I believe that it is not the actual personal care and nursing care tasks provided to assist the family that are the most important factors in the reduction of stress for the caregivers. It is my hypothesis that the most important factor is the ability of the health care system to provide emotional support to the family caregiver. This emotional support might be defined by family caregivers as an acknowledgement of how vital their role is to the care being provided and how tremendously difficult this role must be given that their loved one is dying. The health care system might define this support as the ability to “partner” with the family members in the provision of care. That is, the family members who are the caregivers are an integral part of the plan of care and this plan must include support for them.

### **Family Caregiving**

The role of the family in caregiving is not a new one. Historically, there were few health care facilities and services available. Families cared for their ill family members at home, occasionally with the help of the family physician.

In the early 1900s, there was a shift in the focus of health and medical services from the care of the sick to the treatment of disease (Capra, 1983, p.159). Formal institution-based health care was disease-focused and subsequently, patient-focused. There was no expectation that the family members would have a role in the care, or even require explanation regarding the treatments or care of their family member. Family members were pushed aside in favour of the expert care of health professionals.

In recent years, the importance of the family has again been recognized in some sectors of formalized health services. Hospices and hospitals-without-walls, and in-home

services have been developed to ensure the family is supported so the person who is dying can be maintained through their family's participation in their care. " Palliative care developed, in part, as a response to the inadequacies of the acute care/ biomedical model when applied to the care of patients with a terminal illness" (Dudgeon & Kristjanson, 1995, p.338).

The hospice movement has been instrumental in adopting a holistic approach to palliative care, encompassing both the person who is dying and his/her family's physical, psychological, emotional and spiritual needs (Rando, 1984). Family members are encouraged to have an active role in the care of the person who is dying. They also receive support and attention from the staff who recognize that families experience significant stress when a loved one has a terminal illness. "The hospice community embraces and supports patient, family, and close friends, not only during the final days and weeks of the patient's life, but long after death, offering comfort and consolation to the bereaved" (Stoddard, 1991, p. 192).

The emphasis today is on care at home, with the family members playing an integral role in the care. This emphasis has come about not only in response to the recognition of the importance of the family as a natural support to the dying person, but also because of increased demands on the health care system. "This time the emphasis arises from the press of an aging population and diminishing health care dollars and is supported by a belief that now as in earlier times, elders receive the best care at home" (Keating, Kerr, Warren, Grace, & Westenberger, 1994, p.269). If the elderly receive the best care at home, the same should hold true for younger adults and children who require

health care services. The provincial government, in a document called "Quality Health for Manitobans: the Action Plan," maintained that:

if, by providing home care services, we can reduce the length of time a person has to stay in an acute care hospital by a single day, we save enough to pay for several weeks of home care. The potential returns from investments in lower cost and community-oriented services are huge and experience elsewhere suggests that these services also contribute to improved health outcomes. (Manitoba Health, 1992, p.15)

The provincial government, through the provision of home care services promotes community-based care versus institutional-based care. The expansion of community programs is recognized as a means of responding to consumers' needs. There does not, however, appear to be a strategy in place to determine these needs. Nor is there a structured evaluation of current services such as those available through home care, that addresses the effectiveness of the supports that are provided.

The Manitoba Home Care Program includes family members in the assessment and development of a plan of care. One of the objectives of this program is to support family members as well as the dying person through the provision of services. These services may include assistance with the nursing and physical care of the person who is dying, assistance with meal preparation and household maintenance, and supervision where a person cannot be left alone.

Emotional support is incorporated into the care provided, but referrals must be made to other resources such as the community mental health program when extensive

counselling is required. There are social worker case coordinators within the Manitoba Home Care Program, but their primary function is to coordinate the delivery of services rather than provide direct counselling. The limitation of the social worker role has been a point of frustration for program staff. It is recognized that there is no direct service worker position designated to the provision of psychological and emotional support equivalent to the direct service staff who provide nursing care and personal care functions in the person's home. What appears to be lacking is specific program direction to address the psychological and emotional needs of the dying person and their families beyond the referrals to other resources.

The health care system has not taken into consideration ongoing changes in family dynamics. In the past, it could be expected that the children, especially daughters, would live with, or nearby their parents, readily available to take on the caregiving role. Women have since moved away from their parents, initially following their husband's careers. Now, more women are working outside the home and moving across the country following their own careers. "Changing family structure and demographic evolution, e.g. increased longevity, smaller families, more divorces and separations, more women in the labour market, and geographic mobility" (National Advisory Council on Aging, 1990, p.6) have resulted in a less available natural caregiving group.

Who are the family caregivers providing care to a family member who is dying ? The primary caregiver is generally someone from within the person's immediate family. If there is a spouse, this person is usually the primary source of support for the person who is dying. Adult children typically take on the caregiving responsibility where there is no

spouse or that person is unable to provide the care and the “daughters are more likely than sons to be the primary caregiver” (Crawford, Bond & Balshaw, 1994, p.455). In spite of the changes in family dynamics, researchers are finding that women continue to provide the majority of care. Walker (1986) claims that “family care is a euphemism for care by female kin,[and that] there are powerful normative, ideological and marital pressures on women, especially daughters, to care” (p.31) for family members.

More recent studies show that men's caregiving roles are increasing (Merdinger, 1995). I have also worked with several men, both spouses and sons, who have been the primary caregiver of a family member dying of cancer. It has been suggested that men respond to their caregiving role differently than women, with less physical and emotional involvement (Merdinger, 1995). These findings also suggest that the analysis of caregiving needs may have to reflect gender differences.

### **Reflections from the Field**

I have worked in the Home Care Program in Thompson for the past ten years. During that time I have assisted a number of families who were providing care to a loved one in the terminal stage of cancer. A "successful" death for the loved one was a death with minimal or no pain, and with family members having had the opportunity to work through an anticipatory grief process along with the family member who was ill.

My role with these families was that of coordinator of care services. This involved not only arranging for the provision of care - assistance with personal care, supervision, household tasks, meals, nursing care - but also connecting with other agencies or groups who could offer support to the family on an informal basis. There were also many

opportunities for me to advocate for better care in a hospital setting where the family was feeling that no one would listen to them or answer any of their questions. I was often put in the position of sharing information with the family that may have best come from the physician. As a social worker, I was able to provide supportive counselling and encourage families to finish unfinished business.

Have we been meeting family caregiver needs? As a health care provider, I would like to think so, but sometimes I wonder if health care services are provided in the most effective manner. I would be remiss if I did not acknowledge that there are gaps in the services and supports available. I think there has been tremendous improvement in the last ten years but there are still areas where there could be improvement. Specifically, there needs to be a stronger coordinated effort between both formal and informal service providers. Equally as importantly, we need to identify family caregiver needs and focus the services we can provide in addressing those needs.

### **Summary**

Family members play an important role in the care of a loved one in the terminal stage of cancer, especially with the emphasis on care at home. Responsibilities of the caregiving role can create stress or burden for family members. While there is a desire by the health care system to respond to family caregiver needs, there is some question whether current palliative care services provided through home care programs and other health care agencies are meeting caregiver needs. Health care providers in northern Manitoba have expressed concern that family members' needs are not being met effectively. The needs of family members in relation to assistance and support with the

caregiving role have not been clearly identified. It is important to gain an understanding of these caregiver needs directly from the family members who have been in the caregiving role.

The purpose of this research study is to examine the needs of family members providing care to a loved one in the terminal stage of cancer, and to determine which responsibilities family caregivers perceive as causing stress or burden. A further objective of this study is to explore potential gaps in assistance and support of family caregivers and make recommendations for ways the health care system can be responsive to the needs identified by family caregivers.

The following chapter reviews literature on family caregiver needs and caregiver stress or burden. In addition, the family systems approach to loss is presented to assist the reader in understanding the potential impact of terminal illness on the entire family unit.

## **Chapter 2**

### **Literature Review**

In order to examine the needs of family caregivers, it is important to consider the dynamics of the interactions between family caregivers and health care professionals within the care environment. It is within this environment that life-and-death decisions are made. There is an imbalance in the power over and control of the care environment between health care professionals and family members. Health care professionals have sufficient knowledge and experience with life threatening illnesses to know the consequences of actions or inactions. Family members are emotionally vulnerable entering these situations and rely on the health care professionals to guide them through. They need to trust that they will be given consideration for their role in the care of their loved one and they need adequate information to participate in the decision-making process.

### **Communication and Information Needs of Family Caregivers**

Several studies have examined the interactions between family members of seriously ill or dying persons and health care professionals. Problems with communication between the family and health care professionals have been clearly documented (Degner & Beaton, 1987; Kristjanson, 1989; Northouse & Northouse, 1987; Stedeford, 1981; Wright & Dyck, 1984). According to Stedeford (1981), poor communication, second only to unrelieved pain, causes the most suffering in cancer patients and their families. One of the main problems is obtaining adequate information from health care professionals. Difficulty contacting the physician, constantly having to seek information from staff who are unfamiliar with the person because of shift rotations, and being refused information, are

cited examples of this problem (Bond, 1982; Kristjanson, 1986; Wright & Dyck, 1984).

Early work by Hampe (1975) studied how the spouses of terminally ill persons perceived their own needs and whether these were met. Over half of their needs were not met. The need to have their role in the care of their family member recognized, and to be informed of the impending death was highlighted as a particular area of concern. Grobe, Ilstrup and Ahmann (1981) focused on the learning needs of the family members. They identified family members were dissatisfied with the lack of clear information and instruction specific to the skills they needed to fulfil the caregiving role as a key area of frustration.

In research completed by Kristjanson in an urban Manitoba hospital setting, “families did ... identify the importance of being listened to by health professionals, being included in discussions about the patient's care, and, being given clear information about the patient's condition” ( 1986, p.14), when identifying their needs. Family members also felt it was very important to receive instructions about the various tasks they were expected to perform while providing the care at home.

When family members do not receive adequate information, they feel devalued as participants in the care environment. Their reaction is heightened by the emotional turmoil they are experiencing.

Family members are unnecessarily anxious when pertinent information regarding a loved one's disease, prognosis, and treatment is not conveyed to them. Without adequate and accurate information on which to base their interpretation of situations, family members may easily misunderstand the actions of health professionals. This in turn provokes distrust and suspicion. (Degner & Beaton, 1987, p.97)

If family caregivers distrust health care professionals, they may feel they have lost control and begin to feel alone in the experience. Family members will not feel they are equal “partners” in the provision of care of their loved one and they will doubt the efforts of health care professionals to provide the support they may need to relieve the burden of the caring experience.

Individual professionals, working from a family systems perspective, have made attempts to draw the dying person's natural support system into the realm of care. Overall, however, the formal health care system may not be as responsive to the needs of family members as it could be. It is slow to acknowledge the significance of the role of family members in the care of a person in the terminal stage of illness. Therefore, family members are still not consistently included in the decision-making process (Degner & Beaton, 1987) nor do they receive the information they require, or have requested (Kristjanson & Ashcroft, 1994), to assist in the care of the person who is dying. Further, it is not consistently recognized that family members also may need to be the recipients of care.

### **Caregiver Stress or Burden**

Kristjanson (1993) developed the FAMCARE Scale to measure family satisfaction with terminal care. She took the position that families are the participants, recipients and observers of care. As such, they are in a position to evaluate the care received by the dying person and by family members. She noted that “one source of stress for families is their degree of satisfaction with the care received by the [person] and themselves” (Kristjanson, 1989, p.21).

There is a whole body of research that examines stress or 'burden' on family

---

members as a result of their caregiving role (Kosberg & Cairl, 1986; Oberst, Thomas, Gass, & Ward, 1989; Zarit, Reever, & Bach-Peterson, 1980). The majority of earlier studies examine the family caregiver in relation to an elderly person with a chronic illness, most often with a cognitive impairment. For example, Zarit et al (1980) studied the factors contributing to feelings of burden by caregivers of elderly with senile dementia. They found the burden to be significantly reduced when there were social supports, such as continued contact by other family members and friends, in place. Areas of burden included lack of time for oneself, the excessive dependency of the person with dementia on the caregiver and the caregiver's fears about further deterioration in the person's condition (Zarit et al, 1980). The Burden Inventory Scale was developed as a result of this study. I believe that a number of these factors are equally relevant to, but do not encompass, the burden experienced where the care is provided to a person with a terminal illness. When caring for a loved one with a terminal illness, the caregiver also begins to grieve the impending loss of that person, while at the same time assuming responsibility for providing emotional support to other family members.

More recently, a number of studies have attempted to measure caregiver stress in relation to various stages of cancer from the diagnosis to the terminal stage. The Appraisal of Caregiving Scale and Caregiver Load Scale were developed by Oberst, Thomas, Gass, and Ward (1989) to assess family caregiving demands or load, and to examine caregivers' appraisals of the illness/caregiving experience. The Appraisal of Caregiving Scale is used to measure five broadly defined areas reflecting "potential stress responses associated with caregiving: caregiving tasks, relationships and interpersonal

support, lifestyle, emotional and physical health, and overall personal impact” (Oberst, et al., 1989, p.211). The Caregiver Load Scale measures the amount of time and energy actually expended by family members on caregiving tasks. The most significant result of this study was a positive correlation between the perceived caregiver load, and both harm/loss (where 'damage' has already occurred to the person's wellbeing) and threat (where there is the potential for harm) appraisals of stress. The greater the perceived demands on the caregiver, the greater the sense of stress, and therefore, burden (Oberst et al., 1989).

Oberst et al.(1989) also reported that caregivers “indicate that family caregiving has some positive aspects and often can be perceived as at least partially beneficial for the caregiver” (p.214). Similarly, a study by Cohen, Gold, Shulman, and Zuccherro (1994) reported that the positive aspects of caregiving related to the relationship between the caregiver and the care receiver. Where there was a positive relationship and the reason for caregiving was identified as a sense of duty and love, there was less stress and burden reported. Further, O'Connor (1993) suggests that if the act of caregiving meets the psychological needs of the caregiver, the perceived burden may also be less. Further research is required that focuses on the positive aspects of caregiving. Perhaps, if the caregiver does not feel she/he has adequate social support or assistance with the actual tasks, she/he may perceive the experience as stressful or a burden, which would compete with the positive aspects of caregiving.

Bass and Bowman (1990) studied the transition from caregiving to bereavement. They developed measures of caregiving and bereavement with parallel indicators to assess

three dimensions: the appraised difficulty of the situation, negative individual consequences, and negative family outcomes. The appraised difficulty of caregiving is represented by a three-item index asking respondents whether caregiving is the most difficult problem they ever faced, a problem not understood by others, and a problem that is overwhelming. The measure of the negative consequences of caregiving also uses three items which question whether the caregiver has difficulty with too many demands, getting enough rest, and whether his/her health has deteriorated because of caregiving. The last dimension assesses reports of tension among family members and difficulty getting the family to cooperate in caregiving. The negative outcomes of bereavement are measured using comparable questions. The results of this study show that greater caregiving strain will predict greater bereavement strain.

In their study, Bass and Bowman (1990) argue that their measures focus on perceptions rather than actual activities or behaviours. They also focus on terminal illness as a specific stressful life event, with the difficulties and consequences attributed specifically to caregiving and bereavement rather than to overall feelings of distress. They argue that this is in contrast to other studies which use more global measures of stress. “The perceptual and event-specific measures used for this study were selected because it is assumed that neither caregiving nor bereavement is inherently stressful, but rather the level of stress depends on the individual's subjective definitions” (Bass & Bowman, 1990, p.38). They further suggest that an individual's traits and resources help to define and cope with the stress. I believe one of the most accurate indicators of caregiver stress is the subjective opinion or perception of stress or burden by the caregiver. Regardless of the predicted

outcomes of any interventions provided to reduce the stress or burden, if the caregiver perceives a significant amount of burden, then that burden is real for them.

Recommendations from Bass and Bowman's research support early or pre-death interventions designed to relieve or reduce caregiver burden by addressing family care needs and offering an opportunity for the person who is dying and his/her family members to finish unfinished business and resolve issues within the family. This will, in turn, reduce the strain of bereavement once the person has died. They further recommend that support services for the caregivers do not end at the death but remain in place until the survivors have adjusted to bereavement.

### **Family Systems Approach to Loss**

Family members who experience the crisis of terminal illness face considerable emotional turmoil during the caring process. They are faced with the task of providing physical care and emotional support at a time when they are also grieving their own future losses. Anticipatory grief, the process of acknowledging and accepting impending death, begins when a loved one is diagnosed with a terminal illness and continues until the death of that person. Rando (1986) describes the experience of the family members:

The lack of norms and clearly specified expectations and responsibilities, along with the depletion that results from the stress of demands for major readaptations and investments of self, time, and finances, all contribute to the psychological conflicts, emotional exhaustion, physical debilitation, social isolation, and family discord so routinely reported by those whose loved one is dying. (p.99)

Anticipatory grief is best understood from a family systems perspective. Death of a family member threatens the very existence of a family unit. It presents the most difficult and most painful adaptational challenge a family will have to face. The opportunity to

begin work on the mourning process prior to the death of the family member can reduce the stress after the death and facilitate the adaptation of the family unit to the loss. The dying person has the opportunity to participate in planning for the future with the family. This facilitates the family's ability to reorganize without the guilt of moving on without the family member who dies. The dying person benefits from this opportunity by maintaining a sense of control and membership in the family until death. It also reduces the fear that the family will disintegrate after the person's death. The family systems perspective views loss as a transactional process that changes the interactive patterns of the family and challenges the family's belief system (Rolland, 1990).

Anticipatory grief was originally described in a psychosocial context, with the focus on the individual in the terminal stage of a disease and their reactions to the impending death. The work of Kubler-Ross (1969) and the five stages - denial, anger, bargaining, depression and acceptance - when coping with imminent death is one example. This viewpoint does not address the "disruptive impact of death or threatened loss on a family's functional equilibrium" (McGoldrick & Walsh, 1991, p. 4) which can be best understood within a systems perspective on loss.

According to McGoldrick and Walsh (1988), few system theorists have addressed the issue of loss. One of the most notable contributors is Murray Bowen whose work centers around the role of death in the family. He maintains that the level of emotional integration in the family and the functional importance of the member to be lost are key factors in the family's ability to adapt to the loss (Bowen, 1991).

McGoldrick and Walsh (1991) take this idea further. They propose that loss is a transactional process that occurs over time and that it is important to consider reciprocal influences over generations. "The meaning of a particular death, and individual responses to it are shaped by the family's belief system, which in turn is modified by all loss experiences" (McGoldrick & Walsh, 1991, p.7). They suggest that loss is not only a content issue but also a process issue. "Loss modifies family structure, generally requiring reorganization of the entire family system" (McGoldrick & Walsh, 1991, p.7).

Carter and McGoldrick (1980) developed a Family Life Cycle model which McGoldrick and Walsh use as a framework for assessing family members' adaptation to loss in the past and present. Carter and McGoldrick (1980) postulate that all families go through predictable stages of family life, each stage precipitated by a particular life event. The life event presents itself as a crisis which requires the family to reorganize to be able to move on in its development. This model outlines the stages of family development, identifying the emotional process of transition and the tasks required to progress to the next stage. There are six stages: 1) Unattached Young Adults; 2) Young Couples; 3) Families with Young Children; 4) Families with Adolescents; 5) Launching Children and Moving On; and 6) Families in Later Life. Transitions between stages are the most stressful times for a family unit. Loss or threatened loss challenges the very capacity of the family to adapt to change, especially when the loss compounds the stressors during transitions.

Loss resulting from a death is the most difficult event a family has to deal with. Normal stresses anticipated during transitions between stages are heightened by the threat

of the family unit changing or disintegrating to an unknown form because of the impending death of a family member. McGoldrick and Walsh (1991) use the Family Life Cycle model to assess how a family adapts to loss over time and over generations. "From a family systems perspective, loss can be viewed as a transactional process involving the deceased and the survivors in a shared life cycle that acknowledges both the finality of death and the continuity of life" (McGoldrick & Walsh, 1991, p.1). This process is even more evident when there is an opportunity to anticipate the loss, and work through role reorganization and family structure changes with the family member who is dying.

McGoldrick and Walsh (1991) identify two major family tasks of mourning which they suggest promote immediate and long-term adaptation for family members, and strengthen the family unit as a whole. The first task is the shared acknowledgement of the reality of death and shared experience of loss. If the family is able to communicate their acknowledgement of the anticipated loss in a clear and open manner, this will facilitate adaptation to the loss. Without open, clear communication in an environment of trust and respect, stress will remain high and adaptation will be more difficult.

The second major family task of mourning is the reorganization of the family system and reinvestment in other relationships and life pursuits. When a family member has a terminal illness, they become increasingly unable to fulfil their roles and responsibilities within the family unit. Patterns of interaction change and the family equilibrium is disrupted. The family must begin to reorganize roles and redistribute tasks to meet the instrumental needs of the family. It is believed that appropriate reorganization and task distribution prior to the death of the terminally ill person will allow for better

adaptation after the person's death.

The resumption of adaptive functioning, following a death, is facilitated in a family where vital roles and functions have been apportioned among members in a just and equitable manner for optimal comfort and satisfaction in their performance. This type of apportionment occurs when roles are assumed according to individual need, ability, and potential. In such a case, role assumption is usually explicit and well understood by all family members. When a member of this type of family dies, the critical period of reorganization is not likely to be experienced as a crisis because the family already had a built-in process which allows it to reallocate the role functions of the decedent with minimal difficulty. (Vollman, Ganzert, Picher & Williams, 1971, p.104)

When the family members assume a caregiving role, this is a newly created role structured around the presence of illness in one of the family members. The tasks or activities associated with the caregiving role may not be familiar to the family members. They may not know what is required of them and they may not know how to perform certain tasks. In addition to the stress of demands placed on the family members to assume roles and responsibilities previously carried by the ill person, there is the additional stress of needing to learn new tasks, personal care and nursing tasks, which likely have never been part of the family members' repertoire of skills. Two of the family care needs already identified by Kristjanson (1989) are instruction and reassurance on caregiving tasks.

### **Summary**

The terminal illness of a family member creates a crisis for the family as a unit. A reorganization of the family system occurs in response to this crisis, with family members faced with the stress of assuming responsibilities previously carried by the ill person and the additional stress of learning new skills for their caregiving role.

In-home care programs build in tangible supports for family caregivers. This can include assistance with the physical care of the ill person, household tasks, and some emotional support. The question remains, are these supports addressing family caregiver needs ?

Numerous studies have examined caregiver stress or burden. It has been suggested that caregiver burden is related to the degree to which family caregivers are satisfied with the care and support received by the ill person and themselves. Specific areas where caregivers have not been satisfied include problems with communication between the family and health care professionals, and insufficient social supports. The communication problems include not getting adequate information about the ill family member's condition, and lack of clear instruction specific to the skills they require to fulfil the caregiving role.

In-home care programs provide community-based care with the expectation that the family play a significant role in the provision of care. There is no process in place to identify family caregiver needs and determine whether these needs are being met. This research study will attempt to address these issues.

## Chapter 3

### Research Study

#### Method and Study Design

To undertake this study, an exploratory research design was used involving human subjects in the context of caregiving. Relatively little is known about the care needs of family caregivers where a family member is in the terminal stage of cancer. Because of this, a qualitative research method rather than quantitative method was used (Tutty, Rothery & Grinnell, 1996). The particular method I used was micro ethnography. Ethnography is used to study the ideas, beliefs, knowledge and behaviours of a particular cultural group or particular phenomena associated with that group by “eliciting meaning, experience or perception from the participant’s point of view rather than the researcher’s perspective” (Morse, 1992, p.1). In health care research, a hospital could be considered a cultural group, so could a group of professionals. For this study, the cultural group chosen is the families of persons in the terminal stage of cancer.

This study is considered micro ethnography because it describes a portion or one particular aspect of a cultural group; that is, the needs of the persons identified as the primary family caregivers. “A micro study is a close-up view...of a small social unit or an identifiable activity within the social unit” (Fetterman, 1989, p.38). This research study examines the family caregivers’ world and how they interpret the caregiving experience in the context of interactions with the dying person, the family, friends and the health care system (Kleinman, 1992).

Similar studies using qualitative research methods have been conducted using participants who were family members of a person in the terminal or advanced stages of cancer. One of these studies used in-depth interviews to explore family preferences in location of care, hospital or home ( Brown, Davies, & Martens, 1990). The decision to choose care at home was based on the availability of services and supports provided for the caregiver and the ill person. Howell (1986) conducted a study to determine the impact of terminal illness on the spouse. She used semi-structured interviews to explore the issues and problems of the spouse of the hospitalized person with terminal cancer. Her findings were supported by research conducted by Kristjanson (1990) cited earlier in the report. The descriptive study by Stetz (1987) which examined demands on the spouse of a person in the advanced stage of cancer had similar results to the studies cited earlier in the literature review. These studies provided valuable information in the development of the questions for my research study.

For purposes of this study, the primary family caregiver is defined as the individual family member who is identified by the family unit as having the main caregiving role with a family member who is in the terminal stage of cancer. This is typically the family member who has the closest emotional relationship with the dying person. The primary caregiver may be a family member who resides in the same household as the person who is dying or who has moved into the home to assume this role, or resides in the same community and has daily contact. In some instances, the primary caregiver may even be someone who lives in a different community but travels to visit the dying person and has constant contact by telephone.

Through my past experience, the primary family caregiver is typically the spouse, and if there is no spouse or they are unable, for whatever reason, to fulfil the caregiver role, the daughter or son usually assumes this responsibility.

It is recognized that there may be a large network of family members who assist with the provision of care. However, there is generally one member who has the main, or primary responsibility for this role. It is this caregiver that this study focuses on.

The data for this study were generated by one face-to-face interview with each individual defined as a primary family caregiver. The interviews were one to two hours in length, conducted in a location chosen by each caregiver to maximize her/his comfort level. Caregiver needs and areas of perceived stress or burden were identified through the use of a semi-structured interview using open-ended questions. The interview was retrospective in nature as the person with the terminal cancer had already died and the caregiving role had ceased.

Information from the measures of caregiver burden cited in the literature review were used to develop the open-ended questions used in the interviews. One of the main sources of information was the FAMCARE scale (See Appendix A) developed by Kristjanson (1989 and 1993). Areas explored included: rewarding and challenging aspects of caregiving; effect of caregiving on family, community/social activities, and personal wellbeing; experience with the health care system; and support networks for the caregiver. See Appendix B for sample interview questions and the demographic data outline.

Because of the open-ended nature of the interview, I was able to expand specific areas that were relevant to individual caregivers. For example, where there were issues of

children in the home who were directly affected by the impending death, I was able to gather data related to the supports needed by these children. Further, several of the caregivers had a nursing or health care background. This offered insight into the health care system that may not have otherwise been available.

### **Sample Selection**

A purposeful sample of adults who had been in the role of caregiver of a family member in the terminal stage of cancer served as the primary subjects. As methods of purposeful sampling allow, additional participants could have been selected as determined by the data analysis. However, this was not deemed necessary due to the volume of rich data that was collected from the initial sample. The focus was on the quality of the data generated by the participants' knowledge and experience rather than the number of participants. The desired size of the sample was approximately ten caregivers, each involved in a different caregiving situation. There were, in fact, ten participants in the final sample. One family member from each case was identified as the primary family caregiver as defined above. This person was the participant for the interview.

### **The Sample**

The sample was limited to cases where the person with the terminal illness was an adult and the terminal illness was cancer. The sample was further limited to cases where the person with cancer was deceased at the time of the interview with the family caregiver.

The target group from which the sample was derived was small and was originally dependent on individuals who had been primary caregivers of a family member who had died within the past one month to two years in Thompson. The sample base had to be

enlarged to ensure there were an adequate number of participants to conduct this study. Therefore, although the majority of the caregivers had been in this role within the past two years, there were three caregivers who had provided care at least three and one half years ago. It became evident during the interview process that time did not reduce the caregiver's capacity to recall details of events and emotions that they had experienced during their caregiving role. There was no apparent difference in the quality of information provided by these three caregivers compared to those who had more recently undergone the experience.

In addition, there were two instances where the dying person did not reside in Thompson but the family caregiver did. Although in one of those cases, the dying person did travel to Thompson and received some care by the family member there.

According to the Thompson Region Home Care Program statistics, there were twelve cases where a person who received home care services died of cancer in 1994 (Manitoba Health, 1995). There were other cases that the Home Care Program in Thompson was not aware of where family members managed the total care of their family member without formal supports. I discovered that the Canadian Cancer Society had the most accurate and complete list of potential participants because of their role as an informal support to persons with cancer and their families. The Canadian Cancer Society was able to identify sixteen individuals, twelve females and four males, as potential participants in this study.

There were several reasons for the sample to be made up of caregivers who had completed their caregiving role related to the family member who had died. Past

experience had made me aware that family caregivers are often overwhelmed with the task of caregiving and have little time to give to activities that do not have a direct benefit to the dying person or caregiving experience. It was hoped that they would have more time and energy to answer questions since their caregiving role was completed. I also felt that they would have a unique view of the caregiving experience based on their ability to reflect back on it.

Another benefit of selecting caregivers who had completed their caregiving role was that because these individuals were not currently directly involved with the health care system in relation to their family member, they would not perceive this research study as influencing the services they may have received. This reduces the perception of the "position of power" that the participants might have felt in relation to myself as researcher, as I currently work as the supervisor for the home care program. While these participants may receive services from the health care system for other family members or themselves in the future, they will not receive further services for the family member who was the focus of this study.

One shortcoming of using a group of past caregivers is the potential for there to be an inability by the participants to recall sufficient detail to provide a "true" sense of the experience. It was expected that since providing care to a family member who was dying would likely be a significant life event for these individuals, they would be able to recall details of the experience without difficulty, especially if they were given questions to prompt responses in specific areas.

## **Human Subjects**

The experience of a family member dying of cancer signifies a time of great duress for the family members. Research in this area has to be sensitive to not overburden the families. Research methods should not be time consuming and should be sensitive to the emotional climate of the family. I felt that the methods selected met this criteria. While the semi-structured interview may have involved some degree of emotional risk for the family caregiver, I was able to minimize the discomfort for the participants by providing them the opportunity to express their emotions and discuss their needs in an atmosphere that was nonjudgemental and supportive.

The subjects were told the interview would last between one and two hours in length, recognizing that “interviews during which the subject experiences strong emotional responses can be physically, emotionally, and psychologically exhausting for both the subject and the interviewer” (Cowles, 1988, p.165). Only two interviews exceeded this time frame and did so to allow ample time for the participant to share pertinent information. I was prepared to refer individuals to counselling services through the community mental health program if additional support was indicated in the interview process. This did not become necessary during any of the interviews.

The risks to this group of participants had been weighed against the benefits of this research study. I believe from past practise that individuals who have lost a loved one appreciate the opportunity to share stories about that person, even though some of these may be painful, as it helps to keep their memory alive. Research that explores the needs of family caregivers sheds light on the caregiving experience and is valuable for future policy

recommendations from which other caregivers could benefit. Many of the caregivers interviewed for this study agreed to be interviewed because they felt this research was very positive and necessary to help other caregivers in the future.

The sixteen potential participants for this study received a letter explaining the study and requesting their participation. These letters were distributed by a contact person at the Canadian Cancer Society, an agency related to the health care system and seen as a support to families facing cancer. The contact person was able to identify potential participants without being seen as having a position of power over the care and services they receive. The Canadian Cancer Society was asked to distribute the introductory letter to assist in maintaining the anonymity of potential participants and to reduce the pressure on individuals who may have felt obligated to participate based on past involvement with such health care services as the home care program. Some of the family caregivers may have recognized my name as someone connected to the home care program in Thompson. The potential participants were asked to contact me by mail or phone if they were willing to participate. See Appendix C for the introductory letter and Appendix D for the consent form. Of the sixteen potential participants, ten contacted me and agreed to be interviewed.

The interviews took place between October, 1996 and March, 1997, with the majority of the ten interviews occurring in October and November of 1996.

At the beginning of the interview, an explanation of the study was again given and consent to participate in the study was confirmed. The participants were informed that they could stop the interview at any time or refuse to answer any question. This “processual consent” procedure (Ramos, 1989; Thorne, 1980) is recommended in an

article on ethics by Rosenblatt (1995) where he explains that the initial consent procedure that occurs before the research begins needs to be supplemented because:

It is impossible to inform people fully about what they might experience during a qualitative interview because they cannot truly understand all that they read or are told, because they can only be told abstractly about what they will have to deal with, and because nobody can fully anticipate their reactions in the research situation. ( p. 148)

The interviews were audio taped, with the participant's permission, to assist with the transcribing of the interview. Identifying information was collected prior to the taping and each interview was numbered to correspond with this data.

The participants were assured their participation would not influence the care they may receive from the health care system in the future. The greatest possible effort was made to protect the anonymity and confidentiality of the participants.

The interviews were conducted in the comfort of the participant's home wherever possible, if there was a quiet place away from other family members and interruptions. When requested by the participant, arrangements were made to conduct the interview in a private, quiet area away from their home.

### **Description of Caregivers**

The ten family caregivers that were interviewed for this study all resided in Thompson at the time of the interview. They had been the primary caregiver of a family member who died of a terminal illness, cancer. The caregiving experience had occurred between seven months and two years ago for seven of the participants. Two caregivers completed their role approximately four years ago and one, nine years ago.

In eight of the cases, the care was provided in Thompson. In the other two cases, the dying person resided in another community and the caregiver travelled there to provide care. For nine of the persons dying with cancer, care was received in Winnipeg (hospitals) as well as in their home community.

Of the ten caregivers, nine were female and one male. There were five wives, two daughters, one sister, one step-mother and one husband. The youngest caregiver was thirty-six years of age and the oldest, seventy-nine years of age at the time of the interview. The average age was fifty-one years.

At the time of the caregiving experience, five of the caregivers had been employed full time, three employed part time, one self-employed and one retired. The health status of all the caregivers was reported by them as good at the time of providing care and nine reported continued good health at the time of the interview.

The caregivers provided some information on their ethnicity and religion (see Table 1). Four caregivers reported their ethnic background as English; three as 'Canadian'; one as Irish; one as Icelandic; and one as Acadian. Each caregiver identified a religious affiliation: four were United; three, Roman Catholic; two, Anglican; and one, Baptist. It is interesting to note that two of the persons with the terminal illness were described as having no religious affiliation.

**Table 1: Caregiver Demographic Data**

<b>AGE</b>	<b>ETHNIC BACKGRD.</b>	<b>RELIGIOUS AFFILIATION</b>	<b>EMPLOYMENT</b>
30 - 39 1	English 4	United Ch. 4	Full time 5
40 - 49 4	Canadian 3	Roman Cath. 3	Part time 3
50 - 59 2	Irish 1	Anglican 2	Self-employ 1
60 - 69 3	Icelandic 1	Baptist 1	Retired 1
	Acadian 1		
<b>SEX</b>		<b>REL'NSHIP WITH DYING</b>	
female 9		Spouse 6	
male 1		Child 2	
		Sibling 1	
		Parent 1	

The care recipients ranged in age from thirty-one to eighty-five with the average age being fifty-one (see Table 2). There were four females and six males. The ethnic backgrounds were reported as follows: two as English; three as 'Canadian'; one as German; one as Scottish; one as Irish; one as Dutch; and one as Metis. Two care recipients were reported as having affiliation with the United Church; four, Roman Catholic; one, Anglican; one, Church of Scotland; and two with none.

**Table 2: Care Recipient Demographic Data**

<b>AGE</b>	<b>ETHNIC BACKGRD.</b>	<b>RELIGIOUS AFFILIATION</b>	<b>SEX</b>
30 - 39 1	English 2	United Ch. 2	Female 4
40 - 49 4	Canadian 3	Roman Cath. 4	Male 6
50 - 59 2	German 1	Anglican 1	
60 - 69 1	Scottish 1	Ch. of Scotland 1	
70 - 79 1	Irish 1	None 2	
80 - 89 1	Dutch 1		
	Metis 1		

The duration of the caregiving experience ranged from three weeks to one year and four months. The average length of time spent providing care was eight months.

For six of the caregivers, care was provided in their own home. Of the remaining four caregivers, one moved in to the dying person's home and three caregivers visited the dying person. In nine of the cases, the primary site where care was provided was the home, with up to one month of time spread throughout the caregiving experience, spent providing care in the hospital. In one case, the majority of care was provided in the hospital. Two of the deaths occurred at home, seven deaths in the hospital, and one death occurred on the way to the hospital.

The caregivers in this study could be divided into two groups: six who had minimal exposure to the health care system for themselves or their family members, and four who had worked or were working in the health care field. Even those who had worked in the health care field had minimal exposure to the provision of care to a loved one with a life-threatening illness.

In the households where the care was provided, in two instances, the dying person lived alone; in three instances, the only person living there besides the caregiver was the dying person; in two cases, there were teenage children in the home; in two cases, there were adult children in the home; and in one case, there was another adult in the home. In this last case, extended family also resided in the same household. In five of the cases, there were other family members living in the community, and five where there were no relatives in the same community (See Table 3).

**Table 3: Caregiving Environment Characteristics**

<b>PRIMARY CARE SETTING</b>	<b>DURATION OF CAREGIVING</b>	<b>HOUSEHOLD IN ADDITION TO DYING PERSON</b>
Home 9	< 1 Month 1	None 2
Hospital 1	1 - 2 Months 0	Caregiver only 4
	3 - 4 Months 1	Adolescent Children & Caregiver 2
	5 - 6 Months 2	Adult Children & Caregiver 1
	7 - 8 Months 2	Other Adults & Caregiver 1
<b>LOCATION OF CARE</b>	9-10 Months 0	
Caregiver's Home 6	11-12 Months 3	
Dying Person's Home 4	> 1 Year 1	
- Moved In 1		
- Visited 3		
<b>FAMILY IN COMMUNITY</b>	<b>FAMILY LIFE CYCLE</b>	
	Unattached Young Adult 1	
	With Adolescents 2	
Yes 5	Launching Children 5	
No 5	Later Life 1	

The majority of the family caregivers described in this study fall into two main stages of the family life cycle (See Table 3). The stages, as identified by McGoldrick and Walsh (1988), are 'the family with adolescents' and 'launching children and moving on'. The caregivers in this study had to face many other difficult life events that can occur in these family life stages, at the same time as providing care to the family member that was dying.

### **Data Analysis**

One of the clerical staff from my place of work was hired to transcribe the interview tapes. In the position of clerk for a government office, the person clearly

understood confidentiality guidelines. She was asked to sign a Letter of Understanding indicating a willingness to maintain confidentiality during and after assistance with this study. Care was taken to provide support to the transcriber throughout the time she worked on the tapes as the content of the tapes was emotion laden and the situations described were ones with which the transcriber could easily identify. The audio tapes and transcripts from the interviews were kept secure in a locking filing cabinet at my home.

The raw data from the interviews were coded and analysed manually using a “cut and paste” method. Each transcribed interview was proofed against the audio tape. Categories were drawn from the raw data. These categories were further refined utilizing a method of thematic content analysis similar to the one suggested by Philip Burnard (1991). That is, once each line of the transcripts was coded, categories were derived from the coded data. Since a fairly structured interview guide was used to generate the data, that guide served as the initial organizing framework for the analysis (Sandelowski, 1995). The items from all the interviews were gathered together under each category. The categories were then grouped together under four main themes.

### **Trustworthiness**

The criteria used to judge the adequacy (that is, the goodness and quality) of the research were the trustworthiness criteria developed by Guba and Lincoln (1989). These criteria parallel the rigour criteria used in quantitative research; internal validity, external validity, reliability, and objectivity. The four trustworthiness criteria are credibility, transferability, dependability, and confirmability.

Credibility is “establishing the match between the constructed realities of the respondents and those realities as represented by the evaluator” (Guba & Lincoln, 1989, p.237). That is, the data analysis should capture the “essence” of the phenomenon to the point that someone else asked to categorize the raw data would derive similar categories as the researcher. One technique for increasing the credibility criterion is peer debriefing. Peer debriefing requires that a colleague not involved in the study reviews the data analysis and conclusions as a means of testing the findings (Guba & Lincoln, 1989). This was done with a colleague from the Community Mental Health Program. He reviewed three of the interviews and the coded data from each. Then he reviewed the categories and themes for the appropriate “fit” of the data into these. Further, in order to offset my own bias and subjectivity in relation to the data analysis, I have reviewed the data, categories and themes with my thesis committee members throughout the data analysis stage of my study.

Transferability is considered parallel to generalizability and requires that the researcher provide a complete and extensive description of the study so that it may be applied to other situations (Guba & Lincoln, 1989). Every attempt was made to describe the context and the culture which was being studied through extensive documentation of the sample, setting, data collection procedures and content analysis techniques used. Limitations in transferability of this study will be explored in the recommendations section of this study.

Dependability is concerned with the stability of the data over time and parallels reliability. A clear and detailed description of the study must be made available to outside

reviewers so that they can “explore the process, judge the decisions that were made, and understand what salient factors in the context led the evaluator to the decisions and interpretations made” (Guba & Lincoln, 1989, p.242). The sample, setting, and data collection procedures have remained “true” to the original intent of this study. Any methodological alterations or changes in construction that were made were reviewed with my thesis committee members and explanations have been provided. The categories derived from the raw data and the consequent themes that emerged reflect the major theoretical concepts being studied. “If the categories are well laid out and unambiguous, the coding of the data will achieve a high degree of consistency or reliability” (Dawson, Klans, Guy and Edgley, 1991, p.262).

Confirmability “is concerned with assuring that data, interpretations, and outcomes of inquiries are rooted in contexts and persons apart from the evaluator and are not simply figments of the evaluator’s imagination” (Guba & Lincoln, 1989, p. 243). The use of the participants’ own words to substantiate my interpretations of the data assists to establish confirmability. Both dependability and confirmability will also be tested using an audit process conducted by outside reviewers, namely my thesis committee members.

### **Summary**

A qualitative research study was conducted using a micro ethnographic approach. Participants for the study were individuals who had previously been in the role of family caregiver of a family member in the terminal stage of cancer. The participants all resided in Thompson, Manitoba and the majority of the care was provided in this community and in the home. A semi-structured interview was used to collect data. Transcripts were

generated from tapes of the interview. Every effort was made to maintain confidentiality of the participants.

Categories were derived from the data using an open coding and “cut and paste” method. These categories were then grouped under four main themes. The next chapter describes the major findings of this study.

## **Chapter 4**

### **Findings**

Data from the interviews provided a rich description of the family caregiver experience. Four major themes that emerged from the data were the Emotional Toil and Physical Labour; the Health Care System Personified; Support for Caregivers; and After the Death: Reflections on the Caregiver Experience. The data analysis framework is outlined in Table 4. The link between the categories and themes will become evident in the following description of the data. It is important to note that the caregiving experience is presented from the family caregiver's perspective. The person with the terminal illness had already died and each caregiver had the opportunity, through the passage of time, to reflect on the caregiving experience prior to providing information in the interview.

The family member who assumes the caregiving role is engulfed in the experience; totally consumed by the overwhelming emotions and physical demands that drive them. They are on a "roller coaster," barely stopping to consider the world around them and certainly rarely stopping to consider what their needs are. In spite of this, as caregivers who have gone through this experience, the individuals I interviewed had tremendous insight. They were consciously aware of their needs, what was supportive, what was lacking, and what they would recommend to anyone who is the family caregiver to a loved one who is in the terminal stage of cancer.

**Table 4: Data Analysis Framework**

<b>Data Analysis Framework</b>	
<b>THEME 1 : The EMOTIONAL TOIL And PHYSICAL LABOUR</b>	
<ul style="list-style-type: none"> <li>• Emotional Demands</li> <li>• Emotional Support for the Dying Person - Spiritual               <ul style="list-style-type: none"> <li>- Formal services</li> <li>- By caregiver</li> </ul> </li> <li>• Relationship with the Dying Person</li> <li>• Keeping the Family in Balance - Providing support and structure               <ul style="list-style-type: none"> <li>- Fulfilment of family duty</li> <li>- Practical needs of the household</li> </ul> </li> <li>• Emotional Support for Children</li> <li>• The Physical Aspects of Caring - Personal care               <ul style="list-style-type: none"> <li>- Nursing care</li> <li>- Physical demands</li> </ul> </li> </ul>	
<b>THEME 2 : HEALTH CARE SYSTEM PERSONIFIED</b>	
<ul style="list-style-type: none"> <li>• The Relationship with Health Care Professionals</li> <li>• Knowledge and Understanding</li> <li>• Advocacy Role</li> </ul>	
<b>THEME 3 : SUPPORT For CAREGIVERS</b>	
<ul style="list-style-type: none"> <li>• Friends</li> <li>• Family</li> <li>• The Community</li> <li>• The Social Worker</li> <li>• Spiritual Guidance</li> <li>• Work</li> <li>• Self Care (Coping Mechanisms)</li> </ul>	
<b>THEME 4: AFTER The DEATH: REFLECTIONS On The CAREGIVING EXPERIENCE</b>	
<ul style="list-style-type: none"> <li>• When Support Was Not There...</li> <li>• Bereavement</li> <li>• Advice to Caregivers</li> <li>• Recommendations</li> </ul>	

### **The Emotional Toil and Physical Labour**

The most significant impact of the caregiving experience on the family caregiver is in the emotional domain. For it is here that the caregiver bears the weight of the anguish felt by the dying person, the rest of the family and her/his own grief. The responsibilities of being the primary caregiver are “put upon” the family member. They do not have the opportunity to agree to this role, but there is never any doubt that this is a role they should assume. The relationship with the dying person is one filled with love and dedication, although there is also an element of obligation.

#### **Emotional demands.**

Perhaps the most complex area to understand is the emotional demands related to the caregiving experience. The caregiver is the one who is “in charge” of the dying person’s care. This includes organizing where the care occurs, who provides the care, and ensuring that the dying person’s needs are met. There is no script for this role, no manual that describes the tasks step-by-step and no training. The caregiver and her/his loved one are thrown into a new experience that is complicated and confusing. One of the caregiver’s described it as “standing by helplessly most of the time.” There was also a sense of being alone in their struggles. One caregiver said, “I really felt that everything was on my shoulders.” Another caregiver stated, “I felt that nobody cared enough, it was all me.”

The emotional demand on the caregiver increased when the dying person was hospitalized, especially when this was not where the person wanted to be. There was a strong will on the part of the caregivers to fulfill the wishes of the dying person. Many of

the caregivers were aware that the person wanted to die at home and there was added stress when this could not happen. One caregiver said, "He didn't want to be in the hospital. He was an excellent patient but he gave me a hard time." Some of the caregivers were not that comfortable with the hospital setting. It frightened them. One caregiver correlated the hospital with death.

I hate hospitals. Hospitals to me are where people go to die. And seems to be, well they sure do now. This ward had a big stop sign and then there is this air chamber. And you walk through these doors and you think, oh my God, someone is not going to come out of here and then, of course, he didn't.

Part of the ongoing relationship with a loved one is the giving of support and assistance. The nature of this assistance changes when a person is dying. Suddenly, caregivers found themselves facing the very difficult demands of assisting someone to prepare for death. The persons who were dying in some instances faced their impending death with such clarity that they were ready to make the final preparations before the family caregiver had emotionally prepared themselves.

One day he phoned me at work and said, "We have a date for Thursday night. We are going to the funeral home to pick out my casket." That was tough. I hate funeral homes to begin with, let alone going with your husband to pick out his casket.

The next morning we talked about his death. He asked me what it was like to die. I didn't know what to say. He asked me to promise him that they wouldn't bury him in a suit and tie; just jeans and a shirt.

Many of the persons with the terminal illness were in their forties and fifties when they were preparing for the impending death. At that time of their life, their family unit would not typically anticipate their death in the same way as if they were in their senior years. A couple that had the opportunity to grow old together may, through the natural

course of their relationship, begin preparing for death. This was evident in the interview with the older caregiver. There seemed to be less stress and more preparedness of the impending death. The caregiver found comfort in the opportunity to settle the details of the memorial along with the person who was dying.

He was a lot older than me so we always thought he would die before me. A lot of the plans we made were plans of things I would do when I was by myself. We had made our wills a long time ago so I knew what he wanted done. He wanted to be cremated but he told me I could choose where he was buried. He said, "You could put me in the back of the truck and I could ride around with you and the dog." I told him we couldn't do that because someone might steal him and I'd never know where he was. Dying should be a quiet time. I don't think you should have to be sitting there making a list of things that you want done and stuff that you want people to have and that kind of thing. Then you don't have to sit there and cry and wonder what he would want.

When two people are in a close, caring relationship, the pain and suffering felt by one person is often also experienced by the other person. "It is as if you are in constant pain yourself." For these family caregivers, there was no greater pain than watching a loved one dying of cancer. The caregivers experienced emotional turmoil, standing by helplessly as the person struggled, knowing they could not do anything to help and sometimes wishing it would not go on.

There were times near the end I literally prayed, "please take her tonight." It is very unforgiving, and the hopelessness of it when it gets to the later stages. It comes to the point where you know inside that it has got a hold.

Some of the caregivers experienced an inner conflict in response to the emotional demands placed upon them. Some doubted whether they had done enough to help the dying person. This usually had more to do with the high expectations the family member placed upon themselves, than any demands the dying person placed on them. Other

caregivers felt they had done everything they could and still, the dying person expected more.

Sometimes I don't think I did enough. But I did, I know I did lots. But once in awhile you think, maybe...then I would think, no, I'm not a nurse.

She phoned me crying. I had to leave work several times...so I ended up not working. It can drive you crazy. In the room all the time and every little thing she wanted I used to do. I'm there all the time for her and nobody else. She got so dependent on me.

#### Emotional support for the dying person.

It became the caregiver's responsibility to ensure the emotional support for the dying person was provided by family and friends, the clergy, formal services, or whomever that individual identified as a support. The family and friends who were a support for the dying person were often the same persons who provided support to the caregiver. The support from family and friends will be examined later in the findings when the support the caregiver received from these sources is examined.

#### *A. Spiritual support*

Clergy provided comfort to dying persons who identified the spiritual domain as a support. Spirituality was important in the dying process where it had also been an important part of the person's life before the illness. The religious affiliation seemed to matter less than the opportunity to pray.

He was Catholic. There was a priest that came to see him once then went off on a cruise. But there was a Lutheran minister and she was wonderful. She came to see him all the time.

Ladies from the Cancer Society came to see her once a week, shared their experiences. They prayed with her; she was religious. The priest came by and gave her communion and stuff.

*B. Formal services*

In some instances, the dying person used individuals providing formalized services as a support. This support was more of an additional benefit of the services received rather than a planned part of the services provided. For example, home care workers there to assist with personal care became an emotional support to the dying person. These relationships that developed provided a safe environment for the dying person to express their emotions without adding to the burden of the family caregiver.

The nurses and home care attendants spent time with him without me. He told them things he didn't want me to know. He was concerned about me.

A young home care worker and he hit it off really well; kind of a father-daughter relationship. Probably did things they shouldn't have according to home care, but it was good for him.

There was little or no access to counselling services in the home setting or hospital. There was only one case where a social worker provided support to the dying person and that was through the home care program. In the majority of cases, counselling services were not even offered to the dying person and when they were it was seen as a superficial gesture. In two instances, the social worker offered support but the dying persons did not use it.

The social worker eventually came to see him but he wasn't interested in seeing her. He couldn't see that she had anything for him because he had already had contact with the minister.

At the Cancer Foundation once they got to the end of active treatment she was essentially unloaded. They said they would like to see her but she wasn't well

enough to travel for her mental health. As a consumer she realized those people are run off their feet anyway so you're not going to go in for a social visit. In a way it would have been less distressing to not even have the overtures for mental health. If nothing could happen, maybe it's better to pretend it's just not there, rather than sort of scratch the surface.

### *C. Caregiver as support to dying person*

As a significant person in the dying person's life, the family caregiver also provided support. For each caregiver the provision of support was deeply personal. The emotional support provided was an intrinsic part of their interpersonal relationship and an individualized expression of their love. The opportunity to give support also provided a level of comfort to the caregiver, knowing they could be there, sharing the experience with someone they loved and remaining connected to that person.

I was glad that I was there. I really didn't mind hanging back. I knew when he wanted me, he would let me know. I just wanted him to know I would be there when he wanted to talk, whatever he wanted. At one point, he pushed his mom off and told me to come. So I went over and he cried and I'm snorting and bawling half on top of him leaning over.

He never liked me to leave. There were tons of people there and the only one he wanted around was me. Especially near the end, he said, "just don't leave."

I guess I spoiled him and he spoiled me over the years. He didn't want me to be away from him. I did a lot of work for him at the hospital; washing and turning him. He liked the attention. We had a wonderful relationship. I was thankful I could be there.

It was also a time for heartbreak. There were changes in the dying person that caused a strain between the caregiver and the dying person because the dynamics of their relationship had changed. The dying person became more demanding. There was an urgency to get things done before the person died. The caregiver was not in a position to argue. Even though the caregiver was sometimes hurt by what the dying person said or

did, she/he ultimately understood the reasons behind it.

He wasn't quite the same. He was very demanding. Personality change from the treatment or maybe, "Hey, I don't have long, I want everything done now." I had to jump and do it now. You don't realize you can do this; jump on command. But then you realize the situation. He was trying to get everything in order. I hoped the bank account would hold out. I couldn't say anything because I knew his time was limited and he wanted to do what was best.

The dying persons were losing their independence and had less control of their lives because of the progression of the illness. There were changes in the dynamics of the relationship between the caregiver and the dying person. The family caregiver was in the position of trying to empathize with the dying person while at the same time, grieving the loss of the relationship she/he once had.

I would take her from the bed to the commode. If she had an accident between there and there she would apologize. "Mom, what are you apologizing for. It was an accident. You couldn't help it. It's not like you did it on purpose."

#### Relationship with the dying person

When a loved one is in the terminal stage of an illness, the grieving process for the family members typically begins before the death. It is particularly difficult for the primary caregivers because they are the ones who have the closest, most emotion-laden relationships with the persons who are dying. Their anticipatory grief is focused on the loss of the future of their relationship with the dying person.

That past summer we were walking around and there was this couple and they were old, old, old. And we laughed and we were holding hands and we said someday that is going to be us. We didn't think this was going to happen.

She became extremely depressed and terribly anxious. She really distanced herself; pushed everyone away. I phoned her and told her we would miss her whether she liked it or not. She was crying and mad, didn't talk to me all summer. I was

making a quilt for her then so I sent it to her anyway. I had struggled with the thought of not finishing it before she died. She used it everyday, which was very gratifying for me.

In relationships with open communication there was the opportunity to discuss the future, and the caregiver was able to work through her/his grief with the dying person. Some of the caregivers struggled to hold on to the relationship while simultaneously preparing to let go. The dying person recognized that and gave support back to the caregiver. This support was not always well received or even recognized as being helpful to the caregiver because of their intense sadness, but eventually it was understood.

We would talk about a lot of things, what his wishes were. In fact, he was very hard on me at times. I was actually hurt but I think it was kind of his way to get me started being on my own. He'd say, "We've had a relationship where we've been independent. You'll be okay."

He could phone me and talk to me and tell me his inner most feelings, his inner fears. And I wished many times that it was me that had it, not him because it was not the right order. Near the end he used to say, "Miss me, but let me go."

I loved him, still do. I'm glad to have had the opportunity to be with him at that time. And being able to say goodbye. That is a really good thing. I am grateful for that.

### Keeping the family in balance

#### *A. Providing support and structure*

The primary family caregiver played a major role in "keeping the family in balance." They were often the persons who provided structure to the household and support to the other family members. The anticipated death of a family member was stressful on all of the family members, each with their own way of reacting to it and coping with it. There were struggles and tensions that needed to be dealt with. The

primary family caregiver was expected to maintain some kind of equilibrium in the family during this difficult time. They were the ones the other family members relied on for direction in how to deal with the dying person. The family caregivers felt pressure “to be strong.” This added to the emotional toil of the caregiver.

It was a real rocky time for the family. Her youngest son withdrew; disappeared to his room, slept to escape. Her older son drank, took dope, got mad. She had held the place together. The glue was breaking down. It was bleak. I gave direction to the boys on how to interact with their mother; “Okay, you touch her hand, kiss her, tell her you love her.” Someone had to give them the script.

Our oldest daughter had a particularly hard time with this. She would say, “Why do all these people have to be here. Why can’t we have him all to ourselves.” They had a very close bond and she saw no purpose in life without him here. She said she had things to tell him and I told her she better do it that day. She did. I didn’t know what she told him but it seemed to settle her.

Many of these family caregivers were already dealing with difficult issues in their family lives that were not related to the terminal illness of a loved one. Some of these caregivers were also in a primary role in assisting their adult children to deal with very difficult life issues. The caregivers were required to divide their energy between dealing with these issues and providing care to a loved one who was dying.

We were going through rough times with our youngest at the same time with drugs, alcohol, his own mental health. Switching hats and doing that constantly for a year or so. There was a lot of junk going on at the same time.

He couldn’t stand up to his dad or mom. He just wanted everything to go right. He didn’t have the fight in him. And I was sort of that go-between. He could vent to me.

### *B. Fulfilment of family duty*

There was a sense that the caregiving role fulfills a family duty; an expectation that the family unit looks after their own. This duty can be seen as an obligation guided by the

responsibilities each family member has to the family unit. It is something that is done for another family member with the expectation that it would also be reciprocated if the circumstances were reversed. The primary family caregivers recognized the part they played in fulfilling their family duty, but there was also a deep sense of love that drew them to the caregiving role.

It would have been awful not to be able to do it because, it was my turn. It was part of who I am. She did a lot when our mom was sick, because she lived closer. Family is sort of the first line of priority.

It's more the positive aspects of being a family. I'm the daughter and it was the family. You do whatever has to be done and with pleasure.

We always looked after each other. I had cancer years ago so he looked after me and then I looked after him. Wasn't much difference in the way we cared for each other.

The caregivers' perceptions of other family members' participation in the care was measured by their ability to fulfill this role. Caregivers recognized that brothers and sisters, adult children and even parents had other obligations that prevented them from being present to assist with the care. Often these family members were viewed as a support when they maintained contact with the dying person or made the effort to travel to visit and also when they maintained contact with the primary caregiver to offer assistance when it was needed. Younger adult children actually put their life plans on hold to come home and help with the care. Many of the caregivers reported that they would not have been able to manage the dying person at home if were not for the assistance of these family members.

He had tremendous support from both families. My brother was very, very good. The girls were home for the last while so everyone kind of did shift work. His

brothers and sisters all came to see him when I called and suggested they come while he could still recognize them, talk with him. Each spent five or six days. He really enjoyed their company.

One of the girls stopped university for a year to come home and assist her mother. A couple of her girls were there the last month. In the very last month to two weeks, different people came up; her sister and a couple of brothers. They came for visits and stayed for a period of time. Took turns staying with her at the hospital. Someone was with her all the time.

We were the ones around. My brother wasn't around but he was sensitive to the issues and supportive from a distance. It was probably harder for him being further away, too.

There was some resentment toward family members who did not help out. There were family members within the same community that did not seem to have the same commitment to assisting with the care as the primary caregiver. There was the perception by the primary caregiver that other family members were able to continue to "live their lives" with a degree of normalcy that the primary caregiver felt had been taken away. The primary caregivers made attempts to work through their feelings of resentment in order to cope with their caregiving role.

I was the only daughter. I think that was why it was me and not the boys. Boys aren't going to be able to help her with her panties, wipe her and stuff like that. But, they still could have been there more, even just to sit and talk. Saturdays I go for groceries. One day I could not find one of my brothers to come and help. That was frustrating. It's like they had their lives and I didn't have mine. I got angry. So I phoned them all and told them off and I cried and it felt good. For the next two weeks they phoned everyday asking if I needed anything.

I really felt it was all me. I felt nobody cared enough. His parents had their own life. His brothers and sisters. This was my job and irrational as it was, that is the way it was.

You can get nasty and wonder why his father went out to help a friend instead of visiting his son at the hospital. Then you realize he is trying to protect himself. The pain was so great to see his son dying.

### *C. Practical needs of the household*

In addition to the actual tasks of providing personal care, there were practical tasks related to maintaining the household. This included house cleaning, laundry, making meals, shopping and banking. If these were tasks the person with the terminal illness typically did but could no longer do, they were delegated to or assumed by family members. If no one was able, it was the caregiver's responsibility to access the needed resources from somewhere else.

His brother would cook and clean when he came home but that was every other weekend. I offered to pay for a cleaning lady but his mom said he didn't need it, he liked it messy. I didn't know what services were there so I got ahold of this one lady my son had met when we were there and asked if she could find someone to go and clean his apartment and cook meals. So she used to cook some stuff and bring it over to him.

The boys were supposed to clean but they were never trained, never brought up that way. I had to do what I could during my "lightning visits."

In this study, the majority of the caregivers had the responsibility of maintaining the household prior to the illness of their loved one. Since the majority of the caregivers were women, this is probably best understood within the traditional conceptualization of "women's work." An added responsibility in some cases was paying bills and banking. With the additional tasks associated with caring for the dying person, the continued responsibility of maintaining the household added to the caregiver's burden. Wherever possible, the caregiver sought assistance from family members and then from outside sources. The home care program was able to provide assistance in some cases.

Up until the last four to six months her strength was good so she was able to do most of the housework and that sort of stuff. In the last year, home care came in

once a week so that was a big help; vacuuming, dusting, all the things I don't usually do.

### Emotional support for children

Special consideration needed to be given to the emotional support of the children.

Many of the situations explored in this study involved teenage children or young adults who were directly affected by the impending loss of a parent or a sibling. The primary caregiver assumed the responsibility of ensuring supports were in place for the children. There was almost a feeling of panic that something had to be done to help the children, yet the resources were not readily available for these families.

Kids could use support and I don't know what. They really don't want support from the school counsellor because they don't want to be singled out within the school system.

Providing the comfort and support to the children was an emotion-laden task as often these children were the caregiver's own and their capacity to provide the support was compromised by their own grief process. The children had practical questions that might have seemed irrelevant to the caregiver but still needed to be answered for their own reassurance; for example, "Are we going to live in the same house?" Sometimes teenagers were not forthcoming with their concerns. They went inside themselves to deal with their own grief. This made task of providing support even more difficult. Sometimes the children showed an inner strength that amazed the caregiver. The caregivers' usual way of dealing with their children's struggles was compromised by the wave of emotions that flooded their thought processes.

The weekend was okay; it wasn't okay, but it was okay because he was out of hospital and we had dinner with the kids. Mom made his favourite meal. That's

when he told the girls, he said, "Look, I've got about a year to live." I remember that after the meal we sat in the living room with all the lights out and he told the kids. We were always close. They adored their father so I don't know what this did to them. I know it was hard. This was not nice. The hardest part was seeing him in pain, and he was in pain all the time. I protected them a lot and he did too.

When we got the news that he had died, I had to break it to him [son]. He came in and I didn't have to say anything. He was only fifteen. He just said, "He's gone, mom" and I said, "Yes." He said, "I don't know what I'm going to do. He went too soon." He went downstairs to be alone, spent some time crying then he went out to see his friends. He used to go by and talk to them and I was glad. When we got back from the funeral I did arrange for a school counsellor to keep an eye on him and I told him so.

#### The physical aspects of caring

Finally, the physical aspects of caring are included in this section. It was not the actual physical tasks that consumed the caregiver's energy, but rather having to deal with the incongruence of her/his new role as caregiver compared to the roles and responsibilities she/he had in relation to the person who was dying prior to the illness. There was a sense of imbalance in the relationship. For example, the opportunity to have an equal partnership in caring for each other within an intimate couple relationship, was replaced by a more one-sided caregiving care receiving relationship. The parent had to rely on her daughter for actual physical care at a time when the caregiver still needed nurturing from that parent. The caregiver not only had to face the impending loss of her/his loved one, but also the loss of the role in the family unit that person represented.

Mom was such a clean woman and her hair was always just so. To lose all her hair and having to bath her. Stuff like that was heartbreaking. It was like pieces of her was taken away. She was losing everything.

### *A. Personal care by caregiver*

Caregivers struggled with the expectation that they assist a husband or a mother with bathing, dressing or toileting. These tasks were not part of the normal relationship the caregiver had with the person prior to the terminal illness. In fact, for most of these caregivers, the provision of personal care to an adult was not something they were at all familiar with. The caregivers wondered if they would be able to manage these tasks; that is, know how to provide the care safely. That increased their anxiety and added to the emotional burden of the caring experience. At the same time, because of the very personal nature of these tasks, they preferred to provide the care.

A lot of things you learn you really don't think about, take for granted. Like the bathing. I never thought I would ever be involved in having to help give my husband a bath. Learned how to operate these different gismos for the bathtub. If somebody said I would be changing diapers on an adult I probably would have said, "You're crazy, I'll never do that." But, you never really thought twice. I would rather do it than have somebody else do it.

Taking care of the physical needs. I think you do quite a bit of that. I told them I don't mind all the bathing, all the bowel movements, but I can't deal with the blood. So before I come in the morning, I want you to deal with the blood. My help was more nurturing and being there and cleaning. Of course, you have to be careful. He wanted me to shave him. He could have bled to death. First time I shaved him, I thought, my God, I'm going to kill him. A small nick from an electric razor took hours to stop bleeding.

Some of the caregivers were nurses, or at least had education in the health care field. This gave them an additional comfort level with the tasks they were expected to do. It was something they could give to their loved one as a way to maintain closeness in their relationship.

In the hospital I did a lot of work for him. I didn't want him to have bedsores so I did a lot of washing and turning him. He liked the attention he got. Caring for him

wasn't a problem. I didn't have to learn anything. Changing him didn't bother me. It bothered him more.

*B. Nursing care by caregiver*

Some of the caregivers were also faced with performing nursing tasks. For the caregivers without a nursing background some of these tasks were uncomfortable and confusing. The caregivers had to keep track of a large number and variety of medications. They were also thrown into situations where they witnessed the side effects of medications and procedures and then were expected to assist with the care. Physical suffering - tremors, vomiting, pain, swelling - in a loved one can disarm even the strongest of individuals. The caregivers sometimes felt abandoned by the professionals who were supposed to be there to provide this care. Some of the caregivers were frustrated that they were unable to ensure the nursing aspects of the care were provided. They resigned themselves to the fact that they had to provide the care.

The throwing up, the tremors in the night. Where are the nurses ? Yes, I am here but I can't stand this; can't stand caretaking in this way. His back didn't stop bleeding after the bone marrow biopsy. Always bleeding from this hole in his back and the sheets would just...it was like watching him...there was always blood.

When she got sores on her bum, home care showed me how to look after her. And these plastic see through things with medication and everything. I would watch them do it and then I could do it myself.

Some of the caregivers with nursing backgrounds tried to separate their nursing role from their role as a family member. This would have enabled them to spend their time and emotional energy on their loved one without having the additional responsibility of being the "nurse." For the most part, they were unsuccessful in doing so. It seemed that the health care system relied on their expertise and also relied on them as an "extra part of

hands.” The family caregivers felt obligated to assist out of concern that no one would take their place in assisting with their loved one’s care if they did not do it.

They didn’t know what to do with the feeding tube. It was like they were afraid of it. The replacement doctor expected me to explain everything. If I didn’t, who would have ?

I’d tell him not to tell them I was a nurse. They always seemed to find out. Then they would kind of just leave him; left it to me. But it would have been nice if that was the understanding. Instead, I felt, if I’m not there, no one will be there.

### *C. Physical demands*

The primary caregiver ended up in the unexpected role as hostess. Friends and family would gather at the house to spend time with the dying person and it would be the primary caregiver who had to get the coffee, feed them and sometimes, entertain them. The caregivers found this role exhausting; taking up precious time and energy they saw better utilized addressing specific care needs of the dying person or resting to conserve their energy.

It was very tiring. You don’t realize how tired you are until afterwards. A lot of it was the things you had to deal with. It was not uncommon to have fifteen to twenty people here during the day, just dropping in to visit. Constantly having to entertain. When he went to sleep, these visitors would still want to talk, so there was never any rest time for me.

It used to tick me off, the first few months at home. People would come to visit and sit there like it was a coffee house; from 7 am to 3 am steady going with soup, coffee, sandwiches. I decided to do like a hospital visiting time. So I told her it was too hard. I didn’t have time to do as much for her when I’m out there doing dishes and making soup and sandwiches. They would just sit there and smoke and gossip, not even spending time with her. I told them they could come from 1 to 3 pm and 6 to 9 pm. That was it.

There was also a sense of endlessness to the task of caring. One caregiver aptly described it as “a merry-go-round.” All the caregivers agreed that the role of caregiver

consumed their time and energy. They were exhausted and did not even realize how tired they were. There was little time to reflect on the experience and little time to consider their own needs. They learned to cope by taking one day at a time.

I would go home after work, make supper. I would leave and go the hospital until 9:30 or 10:00 pm. Go home, throw a load of laundry in, get it out and go to bed. Get up the next morning and go to work. It was a routine. I was sort of on autopilot.

You just go, go, go. And there doesn't seem to be an end to it. I was at work, at the hospital and at home. What I remember most is being so tired and no solution for it.

### **Health Care System Personified**

Through this study we learn about the interaction of the family caregiver with the health care system. Developing a relationship with the professional caregivers was very important to the family caregivers, both for themselves and for the person who was dying. To be able to trust these professionals to guide them through this experience; to show compassion and to share knowledge in a way that was reassuring and helpful were paramount to the comfort level each family member had with their role as primary caregiver. Caregivers did not separate the professionals from the health care environment that they work in. The result was that the sense of responsiveness of the health care system to the caregivers' needs was personified in the professionals who work within the system.

## The relationship with health care professionals

### *A. Positive experiences*

Where the caregiver felt a sense of compassion, trust and connection with the health care professionals, the care received by the dying person and the support to the caregiver was perceived as positive.

#### *i. The nurses*

The caregivers had distinct notions of the attributes nurses should have in order to provide good care. They were looking for compassion and warmth in the care provided. They appreciated helpful gestures that went above and beyond the “call of duty;” the provision of a small cot, for example. They felt closer to the nurses who were able to share in their emotions. They described the nurses as “human,” if they showed emotion in reaction to dying and death. Consideration of the family caregivers’ needs was paramount to their definition of good care.

The nurse took my sister and I into a quiet room. We cried together. Nice to know nurses are human; don’t always see that side.

We had one wonderful nurse. We loved her. She had a good sense of humour. It was her personality. She was gentle. There was caring all over the place. Real or imagined, it was there. She just cared and showed it. Probably took more of a personal interest. And the day he died, when we knew he was going to die, she was there.

The care that was provided in Thompson was considered “small town” when compared to the care in Winnipeg hospitals. Some of the caregivers expressed a preference for care in small town hospitals where there was more familiarity with the dying person and “you are treated like a person.” One caregiver felt the relationship that

developed between the nurses and the dying person was two-way. When the dying person showed interest and the willingness to interact with the nurses on a personal as well as professional level, the nurses afforded the dying person more consideration in the care that was provided.

They were caring in Winnipeg but it did not compare to the consideration and understanding in Thompson. I think it is familiarity as well. I don't think the staff here had any more time to spare than the staff down south had. It's just the care, the familiarity with the client and it works both ways. If a client is interested and knows a little bit about you and can interact with you on a personal level as well as a professional level then you are going to have that warmth.

*ii. The physicians*

Positive interactions with physicians were defined by the caregivers as the ability of the physician to respond to their needs. The family caregivers' needs as they related to physicians included maintaining contact and timely responses to concerns about changes in the dying person's health status. Where caregivers reported satisfaction with the care provided by the physicians there was evidence that the physician had established a pattern of contact with the family caregiver through home visits or the telephone. In addition, physicians responded to calls for help by the caregivers in the middle of the night.

The doctor here was tremendous. You could depend on him. He visited once a week. You could hear his truck coming a couple of minutes before he got in the driveway. Every Sunday he dropped in. He was extremely good.

The doctor was able to manage his pain. One really bad night the doctor was there three times. At 3 am I asked if there wasn't anything more he could do. He said the morphine might make him more agitated and make it worse. I said it can't get any worse. He gave it to him and he slept for twelve hours.

### *B. Negative experiences*

Caregivers had little control over the unfamiliar environment of the hospital and reacted with frustration and anger when there was inconsistent or inadequate care. The dying persons faced many indignities at the hands of uncaring professionals. Concerns raised by the caregivers were neither acknowledged nor addressed. Little consideration was given to the family caregiver's role in the care.

#### *i. The nurses*

The caregivers were anxious to develop trusting relationships with the nurses who provided care to their loved one within the unfamiliar environment of the hospital. They felt that if they could trust these health care professionals to provide the care their loved one needed, they would be relieved of some of their burden as sole caregiver. Many of the caregivers were disappointed with the care their loved ones received from the nurses in the hospital setting. Caregivers reported instances when errors were made in treatments. There were poorly trained staff who behaved in an unprofessional manner by complaining about each other, talking "around" the patient and generally not doing their job. All of this resulted in an uncaring atmosphere where the dying person was not treated with dignity and respect.

They didn't know what to do with the tube. It was like they were scared of it. They left him lying without the patch on the tube for one and a half hours. Instead of leaving it open, they could have covered it with a gauze and said when they were coming back or they could have finished the job before leaving the room.

I was very unsatisfied with the nursing care in Winnipeg. She didn't get, she wasn't given the enema, or "go-lightly," whatever they call it before the surgery for some reason. So she soiled her bed and they were mad at her. The humiliation was great. And then when they were getting her up, she was having her menstrual

period and they walked her down the hall with blood dripping down her leg. It was just such a, oh God...in terms of collecting the misfortune it just...if it happened to one person here and one person there, but it just kept coming. I had no idea what the circumstances were. I don't really care.

*ii. The physicians*

Physicians held the key to the health care system for the caregiver. It was the physician who made the diagnosis, determined the treatment and directed the care that was provided. When the physician did not make him/herself available to the caregiver there was a certain level of frustration. When it was believed that the physician made errors in judgement which resulted in misdiagnoses or he/she did not respond to changes in the dying person's condition, the caregiver reacted with anger. The physician was sometimes the scapegoat for all the anger the caregiver was feeling; anger about the unfairness of a loved one dying and perhaps anger that the caregiver's life had been turned upside down by involvement in the caregiving experience.

Why didn't they check him for cancer. The excuse was that they didn't think to look for it in a kid that age. I was very angry at the medical profession, at his doctor for not checking everything first.

I needed a form signed by the doctor for stress leave. I told him my mom was dying and I couldn't think of anything else right now. He said, "Well, everybody has to die" and started telling me his own problems. I slammed the paper on his desk and told him to shove it. After that... maybe he was the one I focused all my anger on.

*C. The home care experience*

The experience family caregivers had with the home care program was different than the nursing care provided in the hospital setting or by the physicians. The caregivers had more control over who delivered the services in their home. If the dying person was

uncomfortable with a particular worker or the worker was not providing care in an acceptable manner, they were replaced. The caregivers did not, however, always have control over the type of service that was offered because of restrictions on what the home care program could provide. Relationships developed with particular workers and as with other parts of the health care system, the satisfaction with the home care program was measured by the personalities and performance of the workers who provided the care.

The home care workers did a wonderful job helping me. They offered twenty-four hour care, but after the first weekend I said we didn't need that much, just someone during the day so he was not alone. I went back to work. Home care was there eight to four, until the girls got back from school. He was happy with his home care workers. It would have been nice for the home care workers to be able to take him out for walks, to get away from the house. But home care is strictly for the home.

There were two home care workers she took to because they were there most, four shifts a week each. She really liked them. There were some workers she said, "Don't you leave me with that one." One worker she complained was too rough. Eventually that worker didn't come anymore. I told somebody to send someone else.

With the provision of home care services, caregivers were faced with the prospect of having to open their home to strangers at a very vulnerable time in their lives. They recognized that this would infringe on the privacy of the family unit. Some family members did not want to share what little time they had left with the dying person with outsiders. The caregivers weighed the discomfort of opening their home to outsiders against their need for help in caring for the dying person.

The hospital suggested home care but dad didn't want no strangers in the house. But I told him I wasn't getting any help from him and I couldn't do it all myself.

**How do I handle this person? They talked about home care but it is something new. You don't know what you think of someone else in your home. Your privacy is taken away.**

**The family caregivers came to appreciate and rely on the assistance from formalized health care services. They realized they would not be able to cope without these services. One caregiver was grateful that the home care services were increased even when family members were staying in the home. With the assistance of these workers, the family members were able to spend more time visiting with the dying person. One of the caregivers became afraid that the services would be taken away if a reassessment of their needs demonstrated the services were no longer required because the dying person had shown some improvement. There was also a fear that if the workers hurt themselves or were not available they would not be replaced and again, the caregiver would be left on his/her own.**

**She needed two people, one home care worker and someone else to lift her out of bed, sit her on the commode and to go to the recliner in the living room. The home care worker would tell me to go out, that she would be fine. I would tell her, no, all I needed was for her throw her back out and then she wouldn't be there tomorrow. Then what would I do.**

**The home care workers became an integral part of the caregiving experience, providing a support that was seen as valuable for the family caregiver. Individual workers developed relationships with the family caregivers and the dying person. They became part of the informal network that surrounded the family unit with support. Workers would visit between shifts or stay longer than the scheduled hours. One caregiver related a tender moment when a night worker stayed into the next shift because she knew the death was**

close. There were even situations where lasting friendships developed out of the initial provision of care.

One of the home care workers developed a friendship with us. Today, I am still good friends with her. She came to the hospital several times on those last few days. She said, "Maybe I shouldn't be here. I only knew her for the last few months." I told her, "You are part of her life. You come."

### Knowledge and understanding

The relationship with the health care professionals described in one sense, how information was shared. The type and content of the information shared by health care professionals to aid the caregivers in increasing their knowledge and understanding was also identified as an essential need by caregivers. Many of the caregivers were interacting with the health care system in a significant way for the first time. To help them perform the tasks expected of them as caregivers, there was a great deal for these caregivers to learn and understand about cancer: the possible treatments, the progression of the illness, symptoms, and even what the death would look like. All this information to be absorbed at the same time as the family caregiver was engulfed in the emotions of losing a loved one. There were challenges for the caregivers. They needed to know what questions to ask and they needed someone there to answer their questions. At the same time, they feared what they may be told.

#### *A. Helpful information*

Some of the caregivers felt they were given adequate information to increase their comfort level with the situation and to provide care to their loved one. One of the caregivers expressed satisfaction that consideration of his needs was given at a time when

it was difficult to think rationally. Some had their questions answered, were included in making decisions about treatment, and were informed of the progression of the illness.

This MRI scan, amazing. They showed me the tumour before radiation, lodged right in the centre of the spine near the brain stem. It was almost like a little snake. And they showed me after and it was smaller. There was never no cure but at least it showed up so small that it never caused her any pain. Anything that went wrong with her or anything that was going to be done, the doctors would explain it to both of us.

### *B. Failure of information*

For the majority of the caregivers, the information provided was not enough.

There were two main problems. There were very few offers from the health care professionals to provide information. It appeared to be the responsibility of the caregiver to seek out information. This was frustrating for the caregivers because often they did not know what to ask. Often, their emotions interfered with their ability to think clearly.

Reading materials were difficult to focus on and therefore difficult to comprehend.

To me, there is a failure as to information. Maybe I didn't know the right people to go talk to. Maybe I didn't ask the right questions. It is so much of a shock. No one offered information.

The second problem was there was no one readily available to answer the caregivers' questions. Many caregivers felt they were imposing on the hospital staff's time. One caregiver said she was reluctant to ask for staff time because they were clearly busy with a large patient load. They recognized staff were "run off their feet" due to staff shortages and did not want to add to their load. For some, the role of the family caregiver was devalued within the health care system. There was minimal acknowledgement of their need for information and they were excluded from the decision-making process.

You don't know anything. You don't even have the questions to ask sometimes. He turned black from the transfusions. Being totally ignorant, I didn't know you could recover from being all black. But no one says, oh, don't worry, that is okay. And that was awful what happened to his mouth. If I had known, I could have made the effort to clean his mouth every day. No one said anything about that. At the end his neck swelled up. I never did ask enough questions because it was too shocking.

The caregivers did not want to always rely on the professionals for information.

They were anxious to seek out individuals with the same type of cancer who would be able to share experiences at a personal level. These individuals were not readily available, however.

There was no one with the same type of cancer for us to talk to. No one outside of the nurses and Cancer Society who could tell me what to expect when I came home. I found that hard.

One caregiver related her experience of receiving the right type of information at the wrong time and the shock that can cause. She was told that her husband would die a painful death at a point when she did not even know he was going to die. The nurse did not take the time to find out what the caregiver knew nor what her emotional state was. Further, there was no consideration given to the fact that the caregiver was in an unfamiliar environment, away from the natural support system she had in Thompson.

This woman came up to me and introduced herself. She was a nurse. She told me to sit down and said her husband had died this way and it is a terrible way to die. She wanted me to know that right away. I didn't even know at that point that my husband was going to die. She said he had cancer on his spine and will be no time at all before it ends up in his brain. She said you've got this and this to expect. That was like, "Welcome to Winnipeg!" This little back ache had turned into a lot more.

### *C. The prognosis*

The most difficult type of information received by the caregivers was the prognosis. This information confirmed for them that their loved one was, in fact, going to die. In many cases, they were also given a time frame of when it could happen. The caregivers agreed that this information was necessary to know so they could mentally prepare themselves for the impending death, but also so they would have time with their loved ones to finish unfinished business.

The doctor told me...I suspected and he confirmed it, that he would not come out of hospital. If you have an honest doctor who is prepared to tell you how things are, then you have time to get your house in order. I think that is important.

Doctors laid it on the line to us, spelled it out. We weren't under the illusion that this was a light illness. We were aware that it was serious right from the start. After the operation the whole family met with the doctor for one and a half hours. We were able to ask all the questions we wanted. The one I asked was how long did she have. He told us then.

We were all there at the hospital when the doctor gave her the diagnosis. We asked if they could operate and he said no; the only treatment was radiation to shrink the tumours, and chemotherapy. And the way he said it first was like she would live five to seven years. And then another doctor came in the afternoon and there was just me and her and my aunt there and he said something else. And then another doctor said something else. There was too much difference from each doctor so I pulled one aside and asked him the bottom line truth. And he told me that she was terminal and only had about a month.

When the time frame of the prognosis was not accurate, it created confusion and mistrust. This was especially true when the time frame was considerably shorter than what the physician predicted. The caregivers were angry at the physicians. They felt deceived; cheated out of precious time. It interfered with their ability to work through their grief.

September they told him, "You've got five years to live. This is malignant melanoma. We think we got it all." On the 19 th of January he saw doctors and

they said to him in those few days he was there that he probably had a year to live, and he was dead in a month.

It's like, accept what I say because you are intelligent and I'm intelligent. Then explain to me why he died when you said he has a year to live. And why was he... you actually said he was getting better on Thursday, and why is he dead on Sunday? You are constantly being, not lied to, but you are told things.

In some cases, the caregiver made the choice not to tell the dying person how long they had to live. They were afraid the dying person would "give up" if they knew they only had a short time left. Sometimes, the physician made the choice not to tell the dying person. There was concern that the dying person would not be able to cope with the information.

I asked him if he really wanted to know how long and he said, "I don't know." I said, "I don't think so because you'll keep thinking about that date." I was afraid that if he kept thinking of that date, he would sort of give up as it got closer. And I wanted him to fight.

She was so scared. That is why the doctor didn't tell her how long. He said they deal not only with the disease, but the person. He thought she couldn't handle everything at once.

#### *D. Preparing for the death*

How does one prepare for death? Given the right information provided in a compassionate way, the impending death may seem easier. In one case that happened. The caregiver and the dying person were able to find comfort in knowing the death would likely be gentle.

He had asked how he was going to die and the doctor told him since he had brain metastasis he would probably just go to sleep. That was comforting. He had thought for the longest time that his liver would continue to enlarge until it just exploded and that would be his demise. This had been in his head for some time.

If the caregiver is not prepared for what may occur in the final hours or moments before death, that time can be disturbing. The memories of that time may interfere with the grief process. One caregiver felt she had not been given adequate information to help her cope with the physical changes that occurred right before her loved one's death. It was a frightening time for her.

The end. I was not prepared for that. The final hours, the way she was breathing. Death rattle. I'll never get it out of my head. No one told me what would happen. I phoned the hospital and asked what to do. They said, "She has signed the directive and doesn't want to be resuscitated. She wants to die at home. If you bring her, it could happen here." I phoned the doctor three times.

#### Advocacy role

In response to the inadequacies of the care provided and out of the need to protect the dying person, the caregiver often assumed an advocacy role. As one caregiver stated, "Often the caregiver is the liaison between the individual and the outside world, and between the doctors and nurses." The caregivers communicated with the health care professionals on behalf of the dying persons. They tried to ensure the care the dying person needed was provided. The challenge was for the caregivers to try and affect change as outsiders in a less than adequate care environment.

She needed a minder, someone to advocate for her and who could be there at the hospital. I was kind of the trail blazer in terms of trying to solve problems. I was kind of the major mover. If something needed doing, I came and fixed it. She was in incredible pain and they brought a piece of equipment that wasn't working. It didn't work and it didn't work. I had to go out and threaten to call the surgeon before they fixed it.

Changes were made at the hospital to accommodate us. They got a larger room with a TV and VCR. I advocated for readmission onto the same ward. I told him something good has come out of this illness, so it has not been a total loss.

### **Support for the Caregiver**

Where did the caregiver get the support they needed? What type of support was most helpful? This theme addresses the support the caregiver received from friends, family, the community, the clergy, the social worker, and from their workplace. There were times when the support provided met their needs, especially when the support came from friends or family. There were more times when there were gaps in the support provided, especially from formal services. Caregivers needed support that was mainly emotional in nature; a sense of “being there” to acknowledge the burden the caregivers were facing. The caregivers needed to know someone would be there to relieve them in whatever way was needed, even if they never actually took advantage of the assistance with the care. Caregivers also looked to their own coping mechanisms to regain control of the situation, although the majority of them admitted they did not do a very good job of looking after themselves.

#### **Friends**

Caregivers talked about the support they received through relationships with friends. There were friends who remained by the caregiver’s side to give them comfort and support. It was the contact with people who cared about them that helped them cope with their caregiving role. These friends helped them “escape,” even if for a brief time, by giving them an outlet to release their emotions and an opportunity to regain their strength and carry on.

I’d be crying, have a good talk and be fine after. It’s great to have a good friend that you can talk to and tell him how you feel, really feel. It makes you feel better.

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Friends came to Winnipeg, visited at the hospital then took me to the hotel. We sat and laughed, drank wine, ate pate. I cried the whole time and it was the best thing for me for them to be there. I'll never forget. I owe them forever for that night.

The caregivers found that there were friends who backed away. These friends could not stay involved because of their own reactions to cancer and death. Caregivers were hurt and disappointed, but understood in a very forgiving way. The hardest part for the caregiver was trying to rationalize their friends' behaviour to the person who was dying and needed them there.

At first, people called to see how he was, then just a few close friends. No one came over. People didn't come because they knew he was dying and didn't know what to say. People are scared. They walk around on tiptoes, felt it would be a horrible, maudlin type experience if they visited.

Some friends had difficulty dealing with her illness. A couple of them stopped coming around. She recognized that and asked why they didn't call. I couldn't really give an answer.

### Family

Some caregivers received support from family members. That was especially true when the caregivers were providing care to a parent or other family member. Their spouses took over the management of their own households. That enabled the caregivers to focus their time and energy on the dying person.

My husband was very, very good. Very supportive. He picked up a lot of the stuff that I wasn't doing. He got groceries, did the laundry, vacuumed, made supper, do the dishes. Some evenings he would come with me to the hospital. When I was late he wasn't angry. There were no fights, no arguing...when I went in he just got up, plugged in the kettle and made me a cup of tea. He didn't say a lot but it was just the things he did were supportive.

The caregivers providing care to their own spouses had the most difficulty getting support from within the family. Many of these caregivers had little or no family in

Thompson and therefore family members would have had to travel great distances to be of any assistance. Family can be a natural source of support and the absence of that resource increased the caregivers' sense of being alone with the caring experience. It is the kind of support we take for granted and often do not miss until it is not there. One caregiver was able to seek refuge with her family while her loved one was in a Winnipeg hospital.

And then I'd go back to my mom's. I have no idea why I did. I could have stayed at a facility near the hospital.

### The community

The caregivers found that their social or community activities were affected by the caregiving experience. For the most part, they were too busy to continue the activities during this time. These activities were seen as unimportant or unnecessary when weighed against the precious little time left to spend with the person who was dying.

Did not think about or do any other activities at that time. I knew we had such a short time, I really didn't think about those things.

Social life? I don't think we had one. No, it was simply home, work, hospital. Went shopping just to get what we needed. There was no window shopping.

There was support from clubs or organizations of which the caregiver or the dying person were a member. Items or tasks that were provided included equipment, house repairs or renovations for a ramp, and food packages. Community members were more comfortable with sharing the dying experience when they could provide something tangible to the family.

Grey Cup weekend, his four brothers were here. I thought, I can't feed them, I just can't. The girls from the Curling Club arrived with two boxes of food. They didn't even know the guys were here, they had just wanted to help. Just when you thought this was enough, someone would come to your rescue.

### The social worker

Several of the caregivers found the support from a social worker integral to their ability to cope with this experience. In a couple of cases, the social worker was part of the psychosocial department of a Winnipeg hospital. Others were community-based. The caregivers recognized the importance of being able to talk about their feelings. They needed a safe, nonjudgemental environment in which to share and to "let go."

I'm pretty strong and I don't sit around feeling sorry for myself. That is not my nature, but I thought, you had better do something or you will go insane. I went down to the psychosocial department and saw a social worker. She was my God-send. Her job was to be there for families. And I just went down there and said, "I have to talk to someone, I have to talk to that person right now." That social worker was my salvation. Without the social worker, I would have gone nuts. A lot of good I would have done.

I saw a counsellor on a very regular basis. That was to deal with other issues though. She was super because there were times when I would go there and I would find myself relaxing. When I got relaxed, I would talk lots, really snorting lots...she just brought out the Kleenex. That was a support because it gave me some sort of relief just to be able to ramble. It braced me a little bit to go home, get supper and go to the hospital again.

### Spiritual support

Spiritual guidance or support was important to several of the caregivers. Some caregivers sought and received comfort and help from a member of the clergy. Others relied on their own inner spirituality to give them strength and guidance. The need for spiritual support was not immediately evident to all of the caregivers. In some instances, the support from a clergy member happened by chance. Some caregivers wished they had thought of it sooner. Those who found comfort in their spirituality were not alone with the burden of the caring experience.

Maybe it was our faith in God by which we were able to deal with this. We are a family of very strong faith. We left it in the Lord's hands. No question that her life was extended a year and a half. I think that carried us through. God looked after me through all this. I didn't have to do a lot for myself.

### The workplace

The workplace became an unexpected source of support for the caregivers, mainly as a diversion. It was a means to focus on something else, a place of refuge or an escape, for a short time.

What kept me sane through this whole thing, kept me balanced was separating work from everything else. I felt it was an intrusion for the home care workers to call me at work to discuss her care. Work was my out.

In most instances when the caregiver had to take time off of work, the employers were very accommodating. One employer who fully understood the magnitude of the crisis the caregiver was facing, advocated for extended sick leave for her. Even co-workers assisted where they could.

I was fortunate at work. There were three women on the spare board anxious for shifts. And there wasn't a time, God bless them, that I ever called that one of them couldn't go at just the last minute. I worked a flexible job. I could have taken a "leave" if I wanted.

There was one case where the family caregiver lost her job because of the demands at home. The caregiver felt trapped in the caregiving role. She was not able to get the support she needed to maintain her job. The workplace would have been an important refuge for that caregiver.

Lost my job because I wanted to stay with her. Couldn't work on weekends because there was only one home care worker available. I didn't realize at the time I could have drawn UIC. I didn't quit my job, they let me go because they couldn't leave my position open. There was no way I could go with a smile and not be worried about what was going on at home.

### Self-care

The caregivers were quick to acknowledge that they did little to look after themselves. Some, however, had the insight during the experience to grab moments for themselves; to use their own coping mechanisms to help get them through the caregiving experience. When the dying person was in hospital, some of the caregivers made the decision not to stay at night. They clearly needed that time to rest. One caregiver said, “Didn’t spend nights there except for a couple; our last night together, that sort of thing. I knew I couldn’t take it.”

Other caregivers found creative ways to look after themselves. One brought her own nutritious food to the hospital. Another kept a diary of everything she was thinking and feeling. One other caregiver found strength in laughter. “Need to find humour. Don’t want to be down in the dumps all the time, even though it is not a happy time. Needed laughter every now and then.”

### After the Death: Reflections on the Caregiver Experience

#### When support was not there

What became overwhelmingly evident from the interviews with the caregivers is that they did not take good care of themselves and they often did not have the support that they felt they needed during the dying trajectory. They were, however, able to identify what would have been a support to them at the time. There was a real sense of feeling alone in the caregiving role in spite of all the family, friends and health care professionals around them. One caregiver described it this way, “And you would sit there and you would cry and there would be nobody to put their arm around you and say, “Hey, it’s

going to be okay.” Other caregivers agreed.

Why am I sitting here in the dark all day and night while this drip goes through and why isn't there somebody else here? What are they doing? Poor me. I wanted someone to take over once in a while. I didn't want to be the most important person there all the time.

Both his and my parents are gone. You feel pretty alone in that big world when all this is going on. Like it would be nice to say, “Hey mom, can you come and give me a hand?” And you don't have that.

No one offered me a lot of help. It seems like you are kind of in this boat on your own a lot of times. Maybe if I went searching a little more. But time was precious. You don't really want to go chasing. I think you are afraid to go out on your own and search it out.

During the experience many of the caregivers were too overwhelmed with the daily demands and the impending loss of their loved one to be able to identify their support needs clearly. Many of them were driven by an expectation they had placed on themselves that they had to be strong for the dying person and the rest of the family. There was a fear that if they stopped, even for a short time, they would become immobilized and unable to carry on.

I just tried to keep busy. I just put myself in high gear and it was like, don't let yourself come down because I knew if I did I would be forced to give up or take time out. It was just sort of autopilot. I tried not to feel. I did pretty good, I succeeded for...no, I didn't succeed. I didn't feel any tiredness or any concern for me. I was totally out of the picture. So, I didn't do anything for me.

I would keep it inside. I think I blew twice, which isn't bad for eleven months. I didn't do a very good job looking after myself. I should have got out more. Sometimes I would think I was going to crack.

In some cases, physical symptoms developed as a result of the stress of the caregiving experience. One caregiver lost twenty pounds in three weeks. Many of the caregivers had difficulty sleeping. One caregiver had limited time to sleep because of the

caregiving demands.

I tried to get a few hours sleep each night. I wasn't even aware that I was tired. It was like being on a merry-go-round. Days and nights just flowed in together and not a lot of rhyme or reason to anything.

Some of the caregivers expressed frustration that their physical needs were not addressed when they approached physicians for assistance. The impact of the caregiving experience on them was not acknowledged even by the physicians who were attending the dying person. They had difficulty getting appropriate medical care and there was little compassion for their needs.

I had trouble sleeping. No one would prescribe anything. They said read a book. I went on no sleep because of tension. Got home from work and my body would go into gear. They were afraid I would become addicted. A mild sedative would have been a big bonus.

The next day after he was diagnosed I had a tremendous migraine headache and I didn't know what to do so I took some of his Tylenol 3. I must have had some kind of reaction to it. I was in pain. The doctors asked me what was the matter. So I told them and they just kind of went on talking about what the treatments were. I'm kind of trying to take it all in and of course you went through a whole day of ordeals and being told this. No sleep, a lot of crying. They didn't say, "Take this or do that," or "Maybe you should talk to so and so." There was nothing. They were just there to tell you about the patient. When people are in the hospital they don't think about the partner. They don't think, hey, these people aren't from Winnipeg, or what you are dealing with, how are you contending, which I think they should give a little consideration.

### Bereavement

As the caregivers reflected on the caring experience, they talked about their grief process and how they were managing at the time of the interview. Some of the caregivers talked about the importance of getting the loved one's affairs in order after the death. Then, as one caregiver suggested, "You can call your soul your own". This would help the

caregiver adjust to the loss and get on with his/her life. Some of the caregivers had wondered if they had done enough to help the dying person, but quickly related that they recognized that it was not healthy or productive to spend the rest of their life doubting what they had done. The hardest part for the caregiver was missing the person who had died.

It was September before I finally discussed him in the past tense. I ended up in hospital. I think it was because I slowed down a bit and everything just crashed in my body. It was just my body telling me I needed a rest. I was off work for three weeks. Sometimes I think now if I had fought more, if I had learned more, maybe he would be alive. I don't want to go through with any friends or family what I went through with him. I don't want to see them go through that. It was so hard when they lowered him. I know it was his body and wasn't his soul, but I'm not going to be able to physically see him, joke with him, talk with him, give him heck, all the things we had before.

This death has made me a stronger person. I always spoke my mind but I have to do it more now. He had a peaceful death. Maybe that is why I'm relaxed about it. He is not suffering anymore. That keeps me going. The second year is harder than the first, especially anniversaries. Memories keep popping up and hitting hard. I can sit and joke with friends, share memories, talk about him up in heaven. It feels good to hear people talk about memories of him and to joke. Some people don't know what to say so they avoid me. Some go a different way downtown. I know they saw me. It hurts when people do that.

#### Advice to caregivers

When caregivers were asked what advice they would give to future family caregivers of a loved one in the terminal stage of cancer, they were very similar in their responses. They were quick to recognize that it is important for the caregiver to look after themselves, even though most of them acknowledged that they did not. Looking after themselves included having someone to talk to, taking time out and physically keeping themselves healthy. They also agreed that the caregiver should access any resources

available to them, whether that is informal support through family and friends, or formal services.

Don't hesitate to talk to somebody, within family or outside, about how you feel. If you keep it inside, it grabs and burns. You feel resentment or "out of sorts." Try not to lose patience. It is not going to be easy. It is really time consuming. Going to find it difficult; there will be times you wish you never started but in the long run, it will be very satisfying.

Do what you feel you want to do within the limitations of your life. They need to know someone loves them. There is a lot of comfort for the helper if you've done what you thought you would like to do. I think it must be really hard to live with "I wish I had, I wish I had, or I should have," that sort of stuff.

Look after yourself. Give yourself as much support as you can. Learn to pace yourself one way or the other, whether it is through having a nurse or family or friends stay with the person if you don't want this person to be alone. You have to be able to look after yourself before you can look after anyone else.

One of the things as the primary caregiver is to accept whatever anybody else has to offer and not be critical when they can't; have no expectations. When someone is dying we don't know how it is affecting everybody and everyone just sort of reacts in the only way they can. As a caregiver you have to be grateful for all the really good things that happen.

Ask an absolute million questions. I don't know if you can prepare yourself with enough knowledge. Ask all sorts of questions and don't be intimidated by anyone. Ask in a nice way though. Be prepared for an awful lot of ambiguity because they often don't know what they are doing.

#### Recommendations from caregivers

Finally, the caregivers offered some recommendations for improvements in the way care is provided in the hospital by health care professionals. One of the most prominent suggestions was in reaction to inadequate sharing of information. The caregivers felt there should be a designated staff person, whether that is a nurse, a social worker or even someone from the Canadian Cancer Society who can act as a patient or family advocate.

Their main or sole responsibility would be to provide information and support to the dying person and the family caregivers. If there was a designated position, these very important responsibilities would not be put aside or forgotten by the other work priorities or demands.

I would like to see from the Health Science Centre - they have been dealing with cancer patients and families forever - when a person walks in, they say, "Look, this may or may not happen but these are the resources available to you." There are brochures there but you haven't got time to sit down and read them. Whatever you can do to alleviate some of the suffering of the caregiver, also helps the patient. Whatever support, help, information, whatever you can give to strengthen that caregiver. Maybe the social worker is the person that has to be there for the caregiver with the information. It is hard because not everyone wants information or needs the same amount of information or as in-depth. The social worker could contact the caregiver, make them aware of the options in terms of knowledge, facilities, etc.

The caregivers suggested there would be improvement in the care provided if there was a way to provide consistency in the staffing. One caregiver suggested that three nurses should be designated to work with one patient, one for each shift. Consistent care was synonymous with compassionate care for several of the caregivers. Nurses must give their patients the time and respect they require. When someone is dying, they must be comforted in a blanket of caring to help ease the dying process for themselves and their family members.

I think there are people out there who are able to say, "Yes, I know this person is going to die and that is okay. I know that and if I care for this person I may grieve their loss even though we have only known each other for a week or two. But knowing that, I'm really good and I'm going to do this because I know what these people need."

The caring is there, but the sensitivity is not. Nurses do not always get it through that they do care even while they have a lot of responsibility and stress. You are there, give time to the patient because they don't get very much attention. I don't

think health care professionals listen to the clients and I don't think they hear them even when they do listen often enough.

### **Summary**

The data from the interviews was sorted into categories under four main themes. The four themes described above did not occur independently of each other. In the true experience of family caregiving, each theme is woven together. Emotional toil and physical labour does not occur independently of the stresses of interrelating with the health care system. Support, or the lack of it, from a host of social systems influence the success of the caregiving experience. One measure of the success of the caregiving experience is the ability of the family member to adapt to the loss after the death of their loved one.

## Chapter 5

### Discussion

The results show that the research methods used in this study were appropriate for this sample population. Qualitative research using semi-structured interviews was necessary to collect sufficient data from a small sample to address the objectives of this study. The micro ethnography approach provided an opportunity to become engulfed in the caregiving “culture,” enabling the collection of data from the perspective of the very individuals who had been family caregivers.

The data collected in the interviews with family caregivers provided a rich base of information to address the three objectives of this research study. The first objective was to identify family caregiver needs within the context of caring for a loved one who is dying. The data analysis framework developed in this study provides an outline of family caregiver needs. The second objective was to identify those caregiving responsibilities which family caregivers perceive as causing stress or burden. It became evident from the interviews with the caregivers that it was not so much the actual tasks of caring but rather the overwhelming emotional nature of the caring experience and the interactions with the health care system, that were at the root of the stress or burden felt by the caregivers. The third objective was to explore potential gaps in assistance and support for family caregivers. The caregivers were able to clearly identify where they felt they received support and where support was lacking. There was clear evidence that there is room for improved support from the health care system.

### **Family Caregiver Needs**

The family caregiver needs identified in this study did not fall neatly into a list that could be checked off as each need is met. Caregiver needs fell broadly into two main categories: the need for support and the need for information. Within each of these broad categories were several components which must be considered and which took on varying levels of importance depending on the individual caregivers. These findings support observations from my past practice, as well as the work of Kristjanson (1989), Degner and Beaton (1987) and others cited in the literature review. Communication problems with health care professionals and the lack of clear information were identified several times as major family caregiver needs that were not met.

#### **The need for support**

As these caregivers had never been in the role of caregiver before this experience, they had no preconceived notion of the kind of support they would require. The definition of support varied from one caregiver to another. Some caregivers defined support as the acknowledgement of their role in the caregiving experience and how difficult that might be. Some described support in the context of being an informed part of the caregiving "team" which included the health care professionals; ie. to have access to enough information and the right information to be able to make informed decisions with the dying person about the treatment and care they received. Some described support as simply a helping hand or a tender word that validated the incredible stress or burden the caregiver felt. Support was also described as the opportunity to talk about the caregiving experience and express their emotions in a caring, nonjudgemental environment.

For the majority of the caregivers in this study, the support they required was not limited to one definition, but rather was a combination of several elements. The caregivers needed and expected the health care professionals to include them in the caring team while at the same time showing the caregivers compassion and concern for their wellbeing. The caregivers needed the opportunity to receive care in the form of support at the same time as they gave care to the dying person.

#### *A. Friends and family*

The caregivers were quite familiar with potential sources of support. As social beings, people learn to rely on family or friends to help them in times of need. That support is inherent to close relationships and is provided without the promise of returned support (Neufeld and Harrison, 1995). Where there is closeness, there is less expectation of reciprocity. One model of reciprocity (Antonucci and Jackson, 1990) suggests individuals in close relationships “bank” their resources while they are younger and healthier with the expectation that as health diminishes or the person experiences a loss, they are able to access support without immediate reciprocity. Social support from family and friends in this study was a positive factor in enabling the caregiver to continue to provide care. There were many testimonies of acts of kindness by friends to whom the caregivers will be forever grateful.

Many of the caregivers in this study did not have extended family readily available to share the caregiving load. Often they were the senior members of the family unit which was comprised of teenage or adult children who were experiencing the same level of loss, or they had siblings who were located in far away places. The caregivers who were

providing care to someone other than their spouse found that their own spouses were their most unconditional source of support.

Caregivers were not prepared for the withdrawal of support by some friends and even family members who appeared to be uncomfortable with dying and death. The withdrawal of these natural sources of support added to the stress the caregivers felt and they responded with a range of emotions including sadness, anger and confusion. Family caregivers had little time to maintain and nurture relationships with friends. The result for some caregivers was the lack of needed social support during that critical time “when extrafamilial relationships could replenish them and give them a respite from the family demands that are so burdensome” ( Rando, 1984, p.339). After the caregiving experience ended, the family caregivers were sympathetic to the emotional turmoil these friends had experienced and some of them were able to rebuild these friendships.

There was anger more so than any other emotion toward family members who withdrew their support. Within the roles and responsibilities of a family unit, there are expectations of how other family members will behave when there is a crisis in the family. There was an expectation by the family caregivers that as part of the fulfilment of family duty each family member would participate in the care of the dying person. Some caregivers were able to recognize that other family members were also grieving the loss of the loved one. Rando (1984) suggests

sorrow is the sadness, pain, and anguish that family members feel in their anticipatory grief over losing a loved one. Many individuals fear that they will be overwhelmed by this mental suffering. Because of this, they may distance themselves emotionally or physically from the dying person (only further contributing to her sorrow) or they may overcompensate with aggressive or

demanding actions to hide their true vulnerability. At times an attitude of indifference is used to camouflage the feelings. ( p.342 )

The primary family caregiver did not necessarily expect that every family member would be able to provide the same amount or type of care, but there was a sense that all family members should at least make themselves available to provide emotional support to the dying person. The family caregiver assumed responsibility for ensuring the dying person's needs were met. When other family members made themselves available to provide support to the dying person, the emotional burden on the family caregiver was lessened. That, in turn, served as a source of support for the family caregiver's own emotional wellbeing.

#### *B. Other supports*

While some caregivers relied on family and friends to provide support, other caregivers relied on formal services like that of a social worker or clergy. There was limited access to the services of a social worker, but when it was available, caregivers claimed the opportunity to talk and "let go" in a caring, nonjudgemental environment kept them emotionally stable and gave them the strength to continue the caregiving role. This supported earlier literature which emphasizes the value of having a supportive environment to express and work through feelings associated with anticipatory grief (Rando, 1984; Rolland, 1991). "Expressing feelings, resolving past conflicts, tending to last wishes, straightening out misconceptions, and recollecting the mutual relationship will create the closure that makes the final separation more peaceful and bearable for family and patient" ( Rando, 1984, p. 341).

The clergy was also a valuable resource for those who sought spiritual guidance and comfort. Chidwick (1988) writes, "People need to find meaning in life. Meaninglessness is, indeed, the greatest spiritual pain" (p.34). When people have the opportunity to evaluate what has been accomplished in their lives, they may reach a sense of peace and acceptance of the impending death of a loved one. Other sources of support included the caregiver's workplace which served as a refuge, and community groups.

Some of the caregivers were able to draw from their own coping mechanisms to maintain control of the situation. For some this meant planning time to rest. For others it meant finding laughter. The caregivers all agreed that they did little to look after themselves. Many of them did not even know how exhausted they were until the caregiving was over. It was best described as a "merry-go-round;" one day blending into the next without end in sight, but each caregiver anxious that the ride would stop too soon, meaning their loved one had died.

#### The need for information

Depending on individual past experiences with and knowledge of the health care system, each caregiver had some ideas of what to expect from various segments of that system. The overall theme was an expectation that enough information be provided to the family caregivers to enable them to make informed decisions about the care their loved ones received. With this information the caregiver could reach a certain comfort level with the care environment that would enable him/her to maintain or regain control of his/her life in a time of crisis.

The family caregivers personified the health care system in their reflections of the caregiving experience. Their satisfaction with the health care system as a whole was based on their interactions with, and the performance of, various health care professionals within that system. Encounters with individual nurses or physicians flavoured their perception of the overall behaviour of the health care system.

*A. Home-based care*

In order to understand the diversity of the caregivers' experience with the health care system, it is important to separate out the care by location; that is, hospital and home. This study did not differentiate the sample by where the care was provided, although the assumption was that care would have been provided mainly at home versus the hospital setting. In nine of the ten cases, this was true although some care occurred in the hospital setting in all cases. It appeared that the experience was quite different when the care was provided in the home than in the hospital. For the most part, the care in the home was seen as very positive.

There was some concern over the loss of privacy when services were first initiated. Once the services were in place, the caregivers expressed great satisfaction with the individuals that provided the care, and described the service overall as supportive and helpful. Sankar (1991) suggests home-based care of the dying can be a very powerful experience because it allows the dying person to continue her/his life as a social being. Sufficient supports must be in place in order to make home death possible.

Helping someone die at home is not something to be undertaken alone by just the caregiver and the dying person. Just as home death represents a tenacious assertion of the dying person's social and cultural identity over the physical reality

of terminal illness, so too is the experience a social one for the caregiver. It is significant not only for the material aspect of the support required (which, to be sure, is of very real importance), but also for the sense of community represented by the support, which helps emotionally sustain the caregiver. (Sankar, 1991, p.195)

There were some comments on the limitations of what services the program could provide. These limitations were a frustration for the caregivers who did not have access to other resources to fill these gaps. The needs that were not met included sufficient household maintenance support (albeit in that instance the services were provided in a different region of the province); the ability of attendants to take the individual on outings, as the services are strictly home-based; and access to a century tub, prevented by liability issues at the hospital and no other resource in the community. Experience from my practise supports these findings. Home care staff experience similar frustrations with limitations in what home care can provide based on program policies and guidelines, and with the lack of other resources in the community to meet these needs.

### *B. Hospital care*

The experience with the hospital system was described in terms of interactions with physicians and nurses. The most tangible measure of the performance of the health care system therefore appeared to be the amount, timing and type of information that was communicated by the physicians and nurses to the family members.

There was a general sense that information was being withheld from the family members. Information around symptoms, side effects of treatment and prognosis were essential to the family caregivers' ability to manoeuvre through the system to ensure their loved ones' needs were being met. Their ability to predict the next challenge within the

caregiving experience was dependent on how prepared they felt. If they had their questions answered, family caregivers were able to assist in the care, report changes in their loved one's condition to the health care professionals and prepare themselves and other family members for the progression of the illness. If their questions were not answered, the caregivers felt the care received was inadequate, they felt devalued in their role as caregiver and there was a sense of dissatisfaction with the health care system as a whole. Degner and Beaton (1987) suggest:

The complexity of the health care system fosters the development of a mystique, particularly when it comes to the treatment of patients with life-threatening illnesses. Patients and their families have difficulty penetrating this mystique, and may even come to believe they have no right to do so. (p.2)

Many of the caregivers felt powerless to influence the care their loved one received. Caregivers recognized that the health care professionals had control over the flow of information and were not forthwith in providing the information, for whatever reason. There was neither the time or energy necessary to negotiate the *right* to this information.

The majority of family caregivers reported "a failure of information." This finding supports several earlier studies (Degner & Beaton, 1987; Kristjanson, 1989; Northouse & Northouse, 1987; Stedeford, 1981; Wright & Dyck, 1984). There was a sense of frustration and anger when information was incomplete or incorrect, not provided in a timely manner and only when requested. The frustration for the caregivers was not knowing the questions to ask. The caregivers can not hope to know what information they need when they have had limited or no experience in providing care to someone who is

critically ill or dying.

When a person is given a diagnosis of terminal illness, the person and the family are in a state of shock. Their emotions flood their thought processes and they have difficulty concentrating. They may be told the information they need to know about what their options are or what the risks of various treatments might be, but until they can get past the shock, nothing makes sense. This may be best understood in the context of the decision-making process.

Although patients and families often respond to life-threatening illness with feelings of fear and grief, this does not imply that they are incapable of participating in decision-making. On the contrary, while responding to the gravity of their particular situation, they are at the same time capable of great moments of courage, generosity, and insight. (Degner & Beaton, 1987, p.93)

The caregivers were angry because the health care professionals did not consider the dynamics of the family unit when they shared information with the dying person. The family caregivers were not recognized as an integral part of the care team. Nor was consideration given to the impact on the caregivers of the information the professionals disseminated.

The physicians were believed to have the most accurate and thorough information. They were perceived as having a position of power which the caregivers found difficult to stand up to. The treatment their loved ones received and ultimately, the determination of the length of life the dying persons had left was in the hands of the physicians. When the person with the terminal illness died in a shorter time than the physician predicted, the caregiver felt betrayed by the health care system. Typically, the caregiver responded with anger directed toward the physician. In some instances, anger was still felt many months

after the loved one's death. The confidence and trust in that particular health care professional, and consequently, the health care system, had been damaged.

The physicians were also described as the most difficult to contact. When physicians did make themselves available, the family caregivers reported that they had all their questions answered. There was considerable variation in the ability of physicians to acknowledge or address the emotional needs of the dying person or the family members. When the physician had a history of care provision with the family, they demonstrated more compassion for the dying person and understanding of the burden on the family unit.

The family caregivers also relied on nurses for information because they were the ones on the ward all the time and more accessible than physicians. The frustration the caregivers had with the nurses was related to the inability of the nurses to take the time to provide information. They did not assume responsibility for communicating with the family caregivers, ensuring they knew what resources were available, and supplying the necessary information about symptoms, side effects, comfort measures and the progression of the illness.

One significant component of increasing the comfort level with the caregiving role, and consequently reduced stress for the family caregiver in the care environment, was the ability of the health care professionals to develop a relationship with the family caregiver. A sense of "connectedness" and trust were necessary for the family caregiver to feel valued, included in the care and comforted in their own grief. It was the antithesis of feeling "alone in the world." One theory of caring (Morse, Bottorff, Neander, and Solberg, 1991) suggests "caring is a mutual endeavour between the nurse and the patient.

When caring occurs, both parties must be communicative, trusting, respectful and committed to each other. The reciprocal interaction means that as the patient is enriched, so is the nurse" (p.80). In the context of this study, the "patient" was the family caregiver. They were the ones in need of mutual caring from the nurses. Unfortunately, many of the caregivers were not able to develop interpersonal relationships with the nurses because the caring was not there.

The caregivers also felt it was important for a relationship with the dying person to be developed and maintained by the health care professionals. The goal of this relationship was to minimize suffering of the dying person. The theory of caring that best describes the nurse's role with the dying person is therapeutic intervention that is patient focused (Morse, et al, 1991). The nurse is able to recognize the individual qualities and needs of the dying person and modify her/his nursing actions to fit these needs (Brown, 1986). This type of nursing is task oriented and can include such activities as "being present in a reassuring manner, providing information, assisting with pain, and spending time with the patient" (Morse, et al, 1991, p.81- 82). Again, family caregivers in this study felt the nursing staff did not meet their expectation of caring. This added to the burden of the caregiving experience because the caregiver felt ultimately responsible for ensuring the needs of the dying person were met.

### **Caregiver Stress or Burden**

In order to clearly understand the needs of the family caregivers, it is necessary to examine the factors that affect the ability of the family member to fulfill this role. It is important to begin with the emotional factors of providing care. For it is in the emotional domain that the caregiver experience envelopes the very being of the family member; it is essence of the caring. The family caregivers consistently reported the need for assistance coping with the emotional demands of the caregiving experience. As described in the data, the emotional demands on the caregiver were great. These family members had been designated as the primary family caregiver by virtue of their close, caring relationship with the person who is dying. They were the individuals that the dying persons relied on to provide emotional and physical support. This is not to say that the family caregivers provided all of the care themselves, but it became their responsibility to organize where and how the care occurred, who provided the care, and to ensure the dying person's needs were met. For the family member, the role of caregiver can be overwhelming.

Who are these family caregivers? Literature suggests that it is typically the women that fulfill this role (Crawford, Bond & Balshaw, 1994). The population of caregivers from which this sample was derived consisted of twelve women and four men, three times as many women. The sample for this study consisted of nine women and only one man. Of the care receivers, four were females and six were males. It may be that there are more men dying of cancer, and if so, one could assume that caregivers who are spouses, are women. In this study, six of the caregivers, including the one male were spouses of the dying person. The other caregivers were daughters, a sister and a mother.

There was some evidence in this study to support the claim that caregiving is assumed to be “women’s work” (Walker, 1986) and therefore they have an obligation to provide the care as part of their role in the family unit. However, in each case there was a loving, natural bond with the dying person that would have precluded any obligation to provide care. Clearly, these women were caregivers out of a desire to do so. Even where there was felt to be an uneven distribution of labour among several children, the primary caregivers did not see themselves needing to be replaced by other siblings, merely supported.

Merdinger (1995) suggests that when men provide care, there is less physical and emotional involvement. It is perhaps unfair to make any assumptions on data collected from the one male in this study. However, there was evidence of considerable emotional involvement in the caregiving role on his part and also physical involvement, although to a lesser degree because there was less of a requirement for it. As stated earlier, the spouses of the women who were the primary caregivers played an important role in providing support to them. They were depicted as being emotionally involved in the caring experience both with the person who was dying and with the family caregiver, through the support they provided.

The family members in this study had a primary role in the care of their loved one. Through the data it was evident that they each had a close and meaningful relationship with the dying person. The very essence of their relationship with the dying person created considerable emotional turmoil for them as they struggled to provide emotional and physical care while they experienced their own anticipatory grief. Also, by virtue of their

designation as the primary caregiver, they assumed a major role in “keeping the family in balance” by providing direction and support to other family members as they faced their own grief.

The Family Life Cycle model (Carter & McGoldrick, 1980) provides a framework to identify expectable family challenges around loss at different points over the course of the family life cycle. The crucial variables that can facilitate or impede the adaptation process include manner of death, life cycle timing of the loss, the sociocultural context, and the functioning of the family. The emotional toil of the caring experience for the family caregiver is deepened by the timing of the event in relation to the life stage of the family. Death is more accepted in a person's late adulthood, when the integration and acceptance of one's own personal and family life, as well as the acceptance of one's own death, are developmental tasks for that life stage (Rolland, 1991; McGoldrick & Walsh, 1991). An untimely death is more difficult to accept and more difficult to adapt to. "Family life cycle timing and social expectations, as well as chronological years, contribute to the untimeliness of a death and the impact of loss on survivors" (McGoldrick & Walsh, 1991, p.18).

One half of the caregivers in this study were in the ‘launching children’ family life stage. It is at this stage that the family experiences “a major transitional upheaval as the two-generational household unit reorganizes as a marital dyad and as a couple renegotiate their relationship, which no longer centers on child rearing” (McGoldrick & Walsh, 1988, p.326). The impending death of the spouse or parent at this family life stage can create an additional crisis for the family unit. Emotional tensions that occur as the family reorganizes

are compounded by the anticipated death. The surviving spouse must prepare not only to face the inevitable loss as the children leave home but also the future alone without a spouse.

Early widowhood tends to be a shocking and isolating experience, without emotional preparation or essential social supports. At launching, the couple reinvest energy in the marriage and make plans for their future together, with the anticipation of sharing activities that have been postponed while child rearing consumed attention and financial resources. With the death a partner, these plans and dreams of a shared future are lost. Other couples and friends who are not yet ready to confront their own mortality and survivorship are likely to distance. The surviving spouse may be reluctant to burden recently launched children who are not yet established or aging parents who have diminished resources and increased needs for caretaking. (McGoldrick & Walsh, 1988, p.327)

The caregivers in the launching children stage experienced many of the emotions that this model outlines. They grieved the lost future as a couple and the chance to grow old together, while at the same time, had grave concerns for the impact of this death on their children.

In one of these cases the adult child was still living at home and in four cases, they had moved away, but came back to assist with the care of their parent. While there may be a tendency for the unattached young adult to deny the importance of family ties at this time and distance themselves for fear of being drawn back into their parents' lives and thereby, lose their autonomy (McGoldrick and Walsh ,1988), the adult children represented in this study returned home for weeks, even months, from as far away as Winnipeg to assist in the care of their dying parent.

There were also two cases in the 'families with adolescents' stage. The crisis in the family unit is in some ways even more evident in these families. Dealing with the loss

or threatened loss of a parent is particularly traumatic in families with adolescents. The adolescent is often in conflict with and struggling to become independent of the parents. When there is a threatened loss, the parents will attempt to draw the adolescents back in to preserve the family unit and to assist with the tasks the dying person is no longer able to do. The adolescent is left with the guilt of having negative feelings toward the parents and resentment that they must put their own activities aside to help out. Adolescents may attempt to escape the pain through acting-out behaviour with their peers such as drinking or stealing (McGoldrick and Walsh, 1988) and some may withdraw. These types of behaviour were evident in some of adolescents and young adults in the families in this study. The inability of the caregivers to “reach” these young people and provide the emotional support they needed added to the emotional burden felt by the caregivers.

One of the key components of family functioning that is central to the family’s ability to adapt to loss is clear and open communication. It is unrealistic to assume that because a family unit has a member who is dying, the family members will be able to communicate in an effective manner. It is important to recognize that at a time when stress levels are very high it is difficult to expect family members to adopt new ways of interacting. Those caregivers who had a history of open communication within the family found it easier to discuss the impending death and to make plans for the future. One caregiver who had a history of conflict with some of the adult children continued to have disagreements with them around how the care should be provided. This resulted in ill feelings that remained after the person had died.

Other life issues and events caused additional burden on the caregivers. They had

to deal with such things as family members with drug and alcohol problems, and a suicide attempt by a family member. One caregiver was providing care to two family members dying of cancer at the same time. While these events had an impact on each caregiver's ability to cope, none seemed to interfere with the caregiver's devotion of as much time and energy to the caregiving role as he/she felt was necessary or desired. In one sense, these other life issues became part of their normal life responsibilities and the caregiving role became the new priority. Bass and Bowman (1990) suggest there may be positive aspects to the caregiving experience which may offset life stressors from other events. Caregiving "may increase closeness among family members who find themselves facing a common problem. Likewise, caregiving and bereavement may force the development of new skills or strengths both in terms of emotional and instrumental capacities" (Bass & Bowman, 1990, p.38). Caregivers may be able to use these new skills and strengths to deal with other life stresses as well.

There were new tasks that had to be done within the role as family caregiver. Besides acquiring responsibilities that used to be part of the dying person's role in the family, there were new responsibilities not typical of anyone's role within the family. Some of these tasks related to the actual physical care of the dying person. For some of the caregivers with health care training, providing personal care to another adult was not new. The difference, this time, it was their husband or mother. Never had any of these caregivers anticipated they would be dressing, bathing or toileting their spouse, or the parent who had cared for them as a child.

The comfort level the family caregivers had with the personal care tasks varied

according to their personalities. Some spouses were very comfortable in this role, and saw it as an extension of a loving couple relationship. In fact, they preferred to provide the care rather than having someone else do it. There were some who tolerated it because it had to be done. One daughter could not bring herself to provide physical care, but willingly did everything else that was needed. It is worth noting that all of the women caregivers in this study had children of their own whom they would have provided physical care to as an infant and child. Perhaps this served to increase their familiarity and comfort level with the physical aspects of the care. There did not appear to be any significant level of stress or burden reported in relation to the provision of physical care.

#### **Gaps in Support and Assistance**

There were very clear messages about where support and assistance were lacking. As described above, the type of support needed included emotional reassurance, open communication and the provision of adequate information. The caregivers were satisfied overall with the support they received from friends and family. There were some instances where intervention from an outside resource would have increased the ability of family and even friends to cope with their discomfort and grief and in turn, be able to support the primary caregiver. The social worker and the clergy were identified as positive and valuable resources but were not accessed or available as frequently as would have been beneficial. Where there was the least satisfaction was interactions with health care professionals in the hospital setting.

The caregivers had concrete ideas about sources of support that could be developed. The majority of the caregivers expressed the need for a patient and family

“advocate” position. This person would have the responsibility of connecting with each person with a terminal illness and their family entering the hospital setting with the sole purpose of providing the information and support they needed. The caregivers were less specific about the qualifications of this person. Some felt the person should be a social worker, while others thought a nurse could fill this role. Carnevali and Reiner (1990) suggest that:

nurses are often the bearers of tidings about the cancer experience, bringing good or bad news about test results or response to treatment. While the physician may give the initial information, it is often the nurse who translates and gives meaning to the findings and how they will affect the patient and the daily living of the patient and the family....Nurses become strong allies - sources of information and support, during hospital contacts and at home. ( p.21)

Rodway and Blythe (1992) suggest the social worker has the necessary skills to fulfill this role. They state that one of the most important functions of the social worker is

the coordination of available resources. Patients facing death can be overwhelmed by the health care system. Health care personnel tend to deal only with their own areas of expertise. Each patient could use someone to lead him or her through the difficult maze of the health care system. Social workers could fulfill that function very well indeed. Their advocacy role could facilitate the successful negotiation of some of the hazards. ( p. 426)

The most significant factor for the caregivers was that this advocate position would be dedicated to providing information and support to the family caregivers and their time would not get consumed with other duties or demands.

The caregivers recognized that each person or family that enters the health care system would have varying degrees of need, depending on their comfort level and past experience. Some would require considerable support throughout the dying experience while others may only need to know someone is there if they need them. This advocate

would also be the liaison between the dying person and their family and the health care professionals. If there were concerns about the treatment or care the dying person received, these would be addressed by the advocate. This would free the family caregivers of that responsibility and afford them the opportunity to concentrate on their relationship with their loved one.

### **Summary**

Two main categories of family caregiver need were identified: the need for support and the need for information. Caregivers acknowledged support from friends and family but identified gaps in support from health care professionals. There was also a failure by the health care system to provide the information needed by family caregivers to be full participants in the caring experience. The lack of support and information from the health care system increased the stress or burden of the caregiving experience. Implications for practice, education and research will be examined in the next chapter.

## **Chapter 6**

### **Implications**

This research study raises serious questions about the ability of the health care system to meet the needs of family caregivers providing care to a family member in the terminal stage of cancer. The caregivers in this study have clearly demonstrated that their needs were not met. This research study supports data from previous studies in Manitoba (Kristjanson, 1989; Degner & Beaton, 1987) with similar subject groups. The recommendations made in the previous studies were echoed by the participants in this study. The implication is that during the past ten years, the health care system has not been able to improve the ability to respond to the needs of family caregivers.

We are facing a crisis in the health care system today. There are demands for all sectors to be fiscally responsible. This has translated into staff cutbacks and bed closures in the hospitals. There is some evidence to suggest physicians may be forced to see as many patients as they can in as short amount of time, and nurses are inundated with administrative work and increased patient loads (Klagsburn, 1994). There is a greater expectation that home care programs provide more services in response to earlier discharges of patients from hospitals. Family members are expected to take more responsibility for the care of their loved ones at home. All this has occurred with little consideration of the needs of family caregivers.

### **Implications for Practice**

This study speaks to the need to develop a specific staff position within the health care system that is dedicated to addressing the needs of the family caregivers and the dying

person. Specifically, this position should provide emotional support and information about symptoms, treatments, and the progression of the illness, as well as act as the liaison between the dying person and their family and the health care system. In addition, there is a need for bereavement follow up for the family. "These important functions cannot usually be assumed by staff within the setting because of their already heavy responsibilities and close involvement in the treatment program" (Degner & Beaton, 1987, p.142).

A role for social work in the support of the family caregiver is clearly evident from this study. It is quite possible that the social worker is the most appropriate profession to adopt the role described above. The social worker would bring the necessary counselling skills to deal with the emotional component and would also possess the appropriate mediation skills necessary to fulfill the liaison role. Social work practice has the dual emphasis of the person and their environment which could "shed more light on the process of palliative care: its social and cultural dimensions, adaptations required by others and the interaction of patients, families, professionals and the larger systems within which they function" (Rodway & Blythe, 1992, p. 429). Hospitals and community health care programs could be encouraged to expand their care teams to include social workers to fulfill this role, not just for persons and families in the terminal stage of cancer but for other life-threatening illnesses as well.

In light of the fact that recommendations for the development of support services for family caregivers have not been actualized over the past ten years, it is also necessary to consider methods of empowering caregivers. They must feel confident enough to

demand the support and information they require from the health care system. They must be supplied with the tools needed to manoeuvre confidently through the caring experience. They must be recognized as an integral part of the care team, afforded full rights within decision-making processes.

Since there is no script for the role of caregiver, perhaps this should be developed. This could include a template of questions that caregivers could refer to as a guide when they are thrown into the mystifying environment of the health care system. There have been some attempts to provide such a template. One such example is, "Cancer and Communication" provided by the Manitoba Cancer Treatment and Research Foundation (n.d.) to persons with cancer and their families. This publication offers this advice:

You need the confidence that comes from a list of sound, practical questions that can be used *to help you communicate and work* with your medical team. You also need to know that it's okay to ask questions and receive answers in terms you can understand. (p.3)

In her book, Dying at Home, Sankar (1991) suggests that there are direct benefits of actively participating in hospital care when the intent is to eventually provide care to the dying person at home. "By gaining experience in decision-making and advocacy, and by establishing direct communication with the physician who will oversee the patient's care from the hospital, the caregiver is preparing for home care"(p. 18). One premise in this book is that nurses and physicians need to be acknowledged for the crucial role they play in the loved one's care. This may not be well accepted by all family caregivers, but for those who can identify the interactive nature of the relationship between the health care professional and the dying person, this opens the way to the development of a relationship

built on trust and respect.

A good nurse will care for the patient regardless of the caregiver's input, but in the case of the dying patient, the extra attention and input of the caregiver can only enhance the quality of care the patient receives. (Sankar, 1991 , p.23)

Further consideration also should be given to the ability of each nurse or physician to provide care to someone who is dying. Because of the intense emotional nature of the dying situation, it is difficult for any nurse or physician not to get emotionally involved. Health care professionals sometimes fear that they will be unable to continue to perform their duties so they avoid emotional investment in their patients and internalize their stresses. "There is the great fear of entering fully into another person's agony, and being overwhelmed by suffering, chaos, and disintegration" (Barnard, 1995, p.22). The nurse or physician can present to the dying person and the family caregiver as cold and uncaring. This can alienate the professionals from their patients.

Nurses and physicians seldom acknowledge how caring for the seriously ill affects them. Perhaps the need to maintain a professional demeanor precludes this. However, reticence to share personal responses openly with colleagues removes a potential source of support. If health professionals could share their experiences, they would feel less isolated while making and implementing difficult treatment decisions. Perhaps then they would no longer have to pretend that losing a patient does not matter. (Degner & Beaton, 1987, p.91)

Health care professionals need the opportunity to debrief; to express their emotions and address the stress and discomfort they may experience working with persons who are dying.

Family members are encouraged to provide as much of the care as they are able, with home care services supporting their role as needed. Home-based programs have clear expectations regarding training the workers are required to have in order to provide

physical care to a dying person. There has been no formal recognition that family caregivers also need training and education to fulfill their responsibilities. There should be a conscious effort to develop strategies to address the learning needs of family caregivers. The learning needs identified in this study include symptom management, comfort measures and physical changes near death. Education for the caregivers should also include assisting them to develop their own coping strategies appropriate to their individual situation.

There is concern that family members are burdened with providing care for their loved one at home as the result of pressure from the hospitals to discharge persons as quickly as possible. There is little consideration for the fact that family caregivers end up providing care twenty-four hours a day without relief when home care services are not readily available. Some caregivers are able to manage this situation while others rely on assistance from external supports. There are circumstances where the caregiver will face incredible emotional and physical demands in order to provide care in a loving manner in a familiar environment in a way health care professionals would not be able to do. It is the challenge of future home care and palliative care programs to provide the necessary assistance and support to the family caregiver to maintain the dying person at home.

There is a need to coordinate palliative care services currently provided by a host of community and health care agencies. The Canadian Palliative Care Association (1995) is working on the development of standardized principles of practice to be used as guidelines for the development of palliative care programs across Canada. These standardized principles propose a client-entered approach to the delivery of care that

meets the expectations and needs of the dying person and their family. The adoption of these principles of practice will occur after a lengthy consensus-building process to be completed in 1998. With the adoption of these principles, there is hope that the needs of the dying person and family caregiver will be given greater priority in hospital and home-based services. It is also hoped that there will be greater efforts to develop comprehensive palliative care services provided by an interdisciplinary team that can move easily between care settings.

The majority of palliative care services in Thompson are provided through the home care program and local hospital with community resources such as volunteers and clergy offering their assistance. This study was undertaken in Thompson to examine the gaps in service specific to northern Manitoba. The results showed that family caregiver needs in Thompson do not differ significantly from those of caregivers in Winnipeg. One difference is that they have access to fewer diagnostic services and treatment specifically for cancer. Therefore, many persons with cancer and their primary caregivers must travel to Winnipeg and are removed from the support of familiar surroundings, family and friends when they are told the cancer is terminal. The impact can be overwhelming and reduces the capacity of the family caregiver to cope with the situation. Health care professionals in Winnipeg hospitals need to be conscious of these special circumstances. Communication lines need to be established not only with the physician but also with home care or palliative care program staff in Thompson who can follow up with the family as soon as they return.

Another gap in supports to the family of the dying person is support for their children. There are no formal resources developed in Thompson to address the needs of the children. Some caregivers identified school counsellors as potential supports, however the children were reluctant to use them as they felt singled out among their peers in the school setting. Resources that have been developed in Winnipeg such as support groups do not translate well to the Thompson region. There has not been sufficient volume of children of parents with cancer to establish a group program specifically for that target population. Strategies to support all children who experience a variety of losses need to be initiated. Potential resources include peer counselling, "bibliotherapy" (the use of books as aids to personal coping), and the use of art or drama (Grollman, 1995).

#### **Implications for Education**

There is a need to educate health care professionals about family caregiver needs and the importance of the family member's role in relation to the care of the dying. If the health care system is to be more responsive to these needs, the health care providers must have a clear understanding of what family caregivers need and expect from the health care system.

One area that has been clearly identified is the need for information. Health care professionals are not providing adequate information to family caregivers. Research by Butow, Dunn, and Tattersall (1995) indicates that communication skills are not emphasized in current training of physicians. "Even when communication is included in medical education, it is often undermined by a widespread perception on the students' part, not infrequently reinforced by their seniors, that this is a minor and insignificant

aspect of the curriculum” (Butow, Dunn, & Tattersall, 1995, p.37). They recommend the development of communication courses and the allocation of resources to deliver the training.

Further, health care professionals need to understand the impact of their actions or inactions from the dying person’s and family caregiver’s perspective. They must recognize the importance of compassion and comfort in reducing the stress or burden of family caregivers. Gregory and English (1994) suggest that there are two requirements by professional caregivers for compassionate care:

First, the caregiver is invited by the sufferer to participate in the suffering experience....Sufferers lead and caregivers follow rather than being in control. A compassionate caregiver does not force himself or herself upon the sufferer. Second, the best and only acceptable response to this invitation is empathetic and authentic caring. The plight of the sufferer is recognized, validated, and embraced. Ultimately, it is the patient and his or her family who work through or make sense of their suffering, not the caregiver. ( p. 21)

### **Implications for Research**

Further research is required which examines the effects of various personality types of dying persons and family caregivers on the nature of care provided by health care professionals. Are there particular characteristics of dying persons or family members that illicit more compassion and consideration than others ?

Research which examines the relationship that develops between the dying person, the family member and the health care professional would be beneficial for understanding the effects of the dying process on the health care professional. What is the health care professional’s capacity to empathize with the dying person and family caregiver given the current state of the health care system ?

This study focuses on one family member as the primary caregiver. The entire family unit is affected by the impending death of a loved one. Research which examines each family member's role and how the family functions and adapts as a unit is necessary to fully understand the impact of the caregiving experience.

Further research with family caregivers is necessary because of the small sample size used in this study. It would be important to ensure all the caregivers completed their caregiving experience within two years of the study to enable better analysis of the results within the context of what was happening in the health care system at the time.

### **Summary**

There are clearly limitations in the ability of the health care system to be responsive to the needs of family caregivers. There are implications for practice, education and research as a result of the analysis of the data collected in this study.

The need for the development of a health care position dedicated to providing support and information to dying persons and their family members is indicated. In addition, health care professionals need to re-examine the way they provide care and the supports they need to help deal with their own stresses when working with dying persons.

## Chapter 7

### Conclusions

#### Reflectivity

Studying family caregivers of family members with a terminal illness has been a highly emotional experience for me. I had the opportunity to enter the very personal lives of individuals who had experienced first hand the death of a loved one. They shared with me their sorrow and pain, their anger and frustration, and every so often, their quiet gladness. I came to understand that the caregiving experience was not done begrudgingly for these individuals but out of deep love for the person who was dying. They were glad to have had the opportunity to share that time in their loved one's life and found comfort in knowing they had provided good care to them.

With the data analysis process I used, I had to listen to the interviews over again, then read and re-read the transcript. Each time, a wave of emotions washed over me and again, when it was time to write up the findings. I came to appreciate what it might be like to work in an area of health care where dying and death occurred day after day. I could understand why some nurses and physicians might want to protect themselves, to stop the sea of emotions from overwhelming them. What I could not understand was the atrocities that some of the caregivers and their loved ones faced at the hands of uncaring professionals. There must always be respect and dignity, if nothing else.

I do believe that it is possible to become emotionally involved in our work with the dying, and survive. You must seek out opportunities to express your feelings in a caring, nonjudgemental environment. This can be done in case debriefings or "death rounds"

where everyone involved in the care of a dying person comes together to reflect and share their experience. I have found that family members of a dying person can also provide a caring, nonjudgemental environment where it is safe to share your grief with theirs. It does not lessen their respect for your role in the care. In fact, they find solace in the compassion you demonstrate.

Researchers who study death and dying must be prepared for the emotional turmoil it can bring. Past experiences with the death of a family member or friend may become vivid again. Unresolved grief issues may cloud the ability to be objective in the analysis of the data. Similarities with the life situations of the participants may give rise to heightened anxiety that something similar could happen to the researcher.

The circumstances of the participants in this study touched me at two different levels. The first was a very personal level. Several of the participants went through the caregiving experience at the age and life stage that I am close to. This made me realize how very fragile our lives can be and forced me to examine the relationships in my life. I realized I did not always consider these relationships as precious as I ought. Because of the nature of the data, the very real, life and death experiences, I also found myself examining my own perspective on life and death.

The second level at which this study touched me was in relation to my work. Since I work in the home care field, I have had the opportunity to provide services to dying persons and their families. The results of this study did not surprise me but I felt the same panic that rises in me from time to time, that something ought to be done. We are desperately limited in our resources and it seems difficult to affect change in the health

care system. Part of what I learned from this study can be incorporated into my work and I will continue to advocate for the development of support services for family caregivers.

### **Conclusion**

The caregiving role is an intrinsic part of the relationship between the family member and the dying person. The potential is there for this role before the threat of illness and death by virtue of the mutuality of the relationship. There is no conscious decision to provide care to a loved one who is dying, rather it is an integral part of “life’s work” in the context of an interpersonal relationship that is valued; to love and be loved. The family caregiver is in a trusted position with the dying person. They become ultimately responsible for ensuring the dying person’s needs are met. Little consideration is given to the needs of the family caregiver. The burden of the caregiving role is deepened by the lack of support and regard afforded by the health care system.

There is societal pressure to define the caregiving role as positive; that is, fulfilling the family duty. That may explain the lack of acknowledgement of the needs of the family caregivers, because, after all, they are not the ones who are dying. There must be consideration given to the tremendous emotional and physical demands of the caregiving role that result in emotional burden on the caregiver. It is not realistic to presume caring for a dying person can be without stress or burden of any kind due to the intense sadness of the situation. The goal of meeting caregiver needs is to reduce that burden. Adequate support must be given if the caregiver is to cope with this role.

The two main areas of need of the family caregiver are the need for support and the need for information. These are intricately woven together throughout the caregiving experience. Family and friends are able to provide some emotional support to the caregiver but there are gaps in this support caused by the other family members' own grief and by friends who are uncomfortable with dying and death.

Formal supports are desperately lacking both in the hospital and community. Nurses and physicians are unable to address the needs of the family caregivers due to the demands of their workload. There is significant concern that professional health care providers do not display compassion and caring in their interactions with the dying person and family members. Support that could be provided by sharing information and acknowledging the importance of the family caregiver's role is desperately lacking.

The development of a support or advocate position that would be responsible for providing information and emotional support to the family caregiver is long overdue. If the family caregiver is expected to play a significant role in the provision of care of the dying person, that caregiver must be supported and acknowledged as part of the caring team. It is possible to reduce the burden of the caregiving experience for the family caregiver which will aid the adjustment to the loss after the death of their loved one.

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**APPENDIX A****FAMCARE Scale***Instructions*

Think about the care that your family member has received. Please answer the following questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D) or very dissatisfied (VD). Please circle the letters below that best match your experience.

*How satisfied are you with:*

1. The patient's pain relief	VS	S	U	D	VD
2. Information provided about the patient's prognosis	VS	S	U	D	VD
3. Answers from health professionals	VS	S	U	D	VD
4. Information given about side effects	VS	S	U	D	VD
5. Referrals to specialists	VS	S	U	D	VD
6. Availability of a hospital bed	VS	S	U	D	VD
7. Family conferences held to discuss the patient's illness	VS	S	U	D	VD
8. Speed with which symptoms are treated	VS	S	U	D	VD
9. Doctor's attention to patient's description of symptoms	VS	S	U	D	VD
10. The way tests and treatments are performed	VS	S	U	D	VD
11. Availability of doctors to the family	VS	S	U	D	VD
12. Availability of nurses to the family	VS	S	U	D	VD
13. Coordination of care	VS	S	U	D	VD
14. Time required to make a diagnosis	VS	S	U	D	VD
15. The way the family is included in treatment and care decisions	VS	S	U	D	VD
16. Information given about how to manage the patient's pain	VS	S	U	D	VD
17. Information given about the patient's tests	VS	S	U	D	VD
18. How thoroughly the doctor assesses the patient's symptoms	VS	S	U	D	VD
19. The way tests and treatments are followed up by the doctor	VS	S	U	D	VD
20. Availability of the doctor to the patient	VS	S	U	D	VD

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**APPENDIX B****Sample Questions for Open-Ended Interview and Demographic Data Outline****Sample Questions for Open-Ended Interview**

1. Please tell me the story of \_\_\_\_\_'s illness.
    - 1a. What was your involvement in \_\_\_\_\_'s care ?
  2. Describe the things that were most challenging to you while providing \_\_\_\_\_'s care.
    - 2a. Were there particular things you had to learn ?
    - 2b....were offered the opportunity to learn ?
  3. What were the positive or rewarding features of providing care ?
  4. Describe your experience with the health care system - the physicians, the hospital, community services/ agencies.
  5. Prior to caregiving, were your experiences with the health care system positive or not ?
  6. What was it like to be a caregiver.
  7. Describe the things you did to help look after yourself.
  8. Did family life change while \_\_\_\_\_ needed care ? Can you talk about that ?
  9. How did caregiving affect your activities in the community ?
  10. What about social activities? Contact with friends and other family members ?
  11. There are many kinds of support (informal and formal) that people can draw upon.  
  
Where did you get support from ?
    - 11a. Were there areas where you could have used more help ?
  12. Did you have concerns about \_\_\_\_\_'s care ? Can you explain.
-

(Appendix B continued)

13. If \_\_\_\_\_ was in hospital for awhile, and at home for awhile, how did the care differ ?

13a. How did your role change ?

14. If you had the chance to give some advise to someone beginning the caregiving role for someone in their family, or tell them what to expect, what would you say ?

15. Is there anything more you would like to add ?

### **Demographic Data Outline**

<b>Person with Cancer</b>	<b>Caregiver</b>
age	age
sex	sex
SES	employment
ethnicity	ethnicity
rel'nship to caregiver	rel'nship to pt.
illness duration	health status
from first diagnosis	
from terminal stage	
cancer sites	
primary care site (home/hospital)	

### **Other Information**

Family life stage

Members in household

Family in community

Affiliations with church, clubs, organizations of person dying and caregiver.

Date of death

Place death occurred (home/hospital)

## APPENDIX C

### Letter of Introduction to Study for Potential Participants

To Whom It May Concern;

As part of my studies to obtain my Masters in Social Work degree, I am conducting research to examine the needs of family members providing care to a loved one in the terminal stage of cancer. You have received this letter because the sender recognizes that you have had the role of caregiver of a family member who is now deceased.

Being a family caregiver means taking the major responsibility for the care of a loved one who is dying. Providing care can be difficult. I would like the opportunity to meet with you to understand what it meant for you to be a family caregiver and what care needs you may have recognized for yourself during the experience.

The interview would be 1 - 2 hours in length at the place of your choice. I would ask you questions which you can choose to answer or decline. The questions would look at the kinds of tasks you did as a caregiver; the most difficult things, and the rewarding things. I would also look at the supports you received and where more, or a different kind of help, would have been beneficial. A follow up interview may be required to ensure I have a clear understanding of the ideas expressed.

In order to complete my thesis, I will have to record your responses to the questions. I will make every possible effort to keep all the information I gather confidential and no identifying information will be shared with anyone else. Codes will be used to identify the interview and names will be deleted or changed in the documentation. Where a direct quotation would provide a clearer understanding, your permission would be obtained and the material reviewed with you prior to its usage.

I currently work in the Home Care Program. However, the research I am conducting is not connected to my work. While I hope to be able to apply what I have learned to improve the services the Home Care program can provide to terminally ill persons and their families, the results of this research will not influence the provision of any future care you or a family member may require from the health care system.

If you are willing to participate in this research project, please return the enclosed form in the addressed, stamped envelope provided, at your earliest convenience or phone me at xxx-xxxx (evenings).

I understand that the death of a loved one is a very sad time for you and your family, and I sincerely appreciate the time you have taken to read this.

For more information, please call xxx-xxxx (evenings).

Sincerely,  
Linda Sundevic

**APPENDIX D**

## Letter of Consent

## Consent to Participate

I agree to participate in the research project, **Examination of the Care Needs of Family Members Providing Care to a Family Member in the Terminal Stage of Cancer**, under the following conditions:

1. I may withdraw from the project at any time without sanction.
2. I may decline to respond to any individual questions within the interview.
3. My anonymity will be maintained throughout the documentation with the use of code names and numbers.
4. Information I provide will be kept confidential by the researcher and shared only with the typist responsible for transcribing the interview.
5. Tapes from the interview will be erased after the transcript is made.
6. Any direct quotations requested for the final report will be reviewed and approved by me prior to the submission of the report.
7. The report will be made available to me, if requested, once the study is complete.
8. My participate in this research project will not influence the provision of any future health care for my family members or myself.

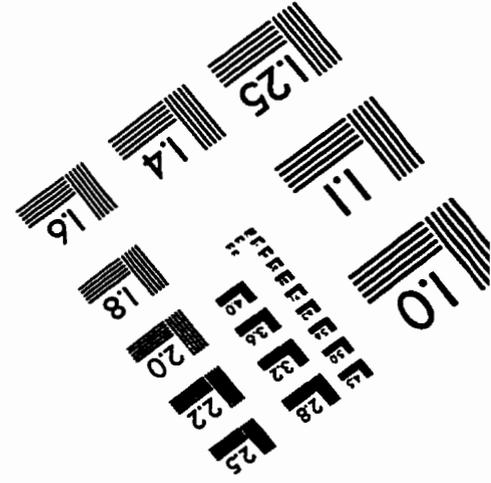
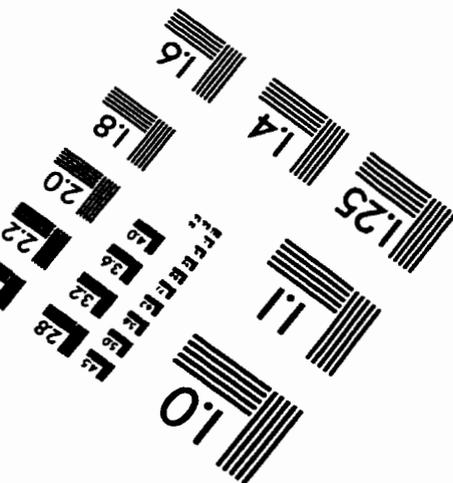
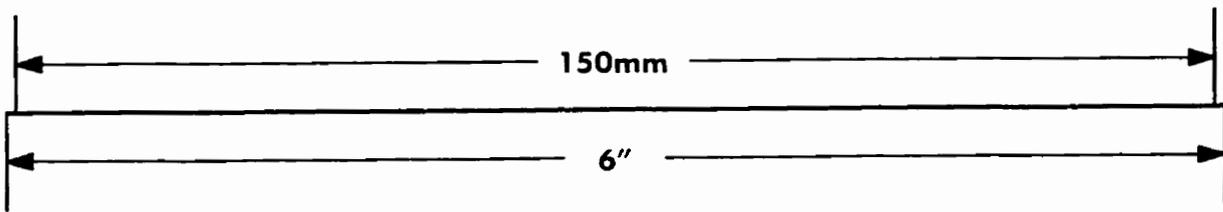
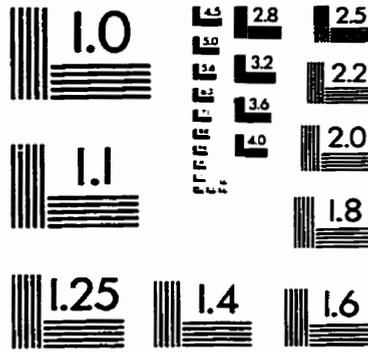
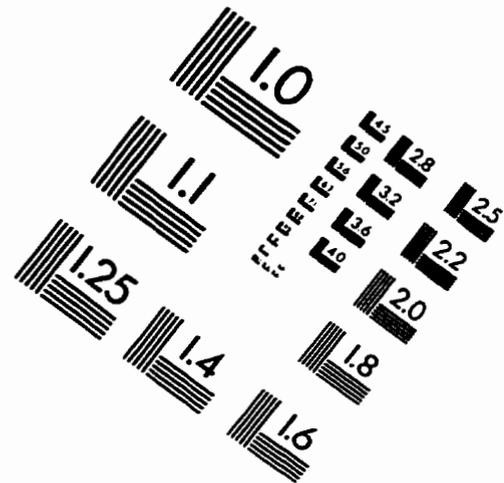
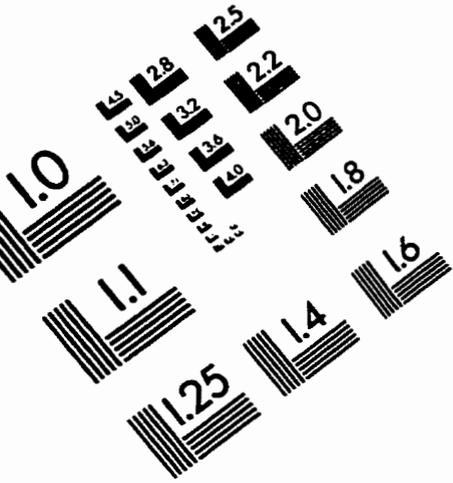
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Signature

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Date

# IMAGE EVALUATION TEST TARGET (QA-3)



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