

DYING AT HOME:
THE EXPERIENCE OF FAMILY CAREGIVERS

by

GAIL M. REMUS

A thesis
presented to the University of Manitoba
in partial fulfillment of the requirements
for the degree of Master of Nursing
School of Nursing
University of Manitoba

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ABSTRACT

The purpose of this study was to gain a better understanding of the primary caregivers and how they were able to care for a terminally ill family members at home. An exploratory - descriptive research design was implemented along with the ethnograph computer program which was used to facilitate the processing of the qualitative data. The conceptual framework for this study was provided by the crisis theory model. The study involved in-depth interviews with thirty caregivers: fifteen had cared for a terminally ill family member at home until death, and fifteen had cared for the terminally ill family member at home but where the family member returned to hospital to die. The findings of the study were summarized into three categories; 1) self - perceived strengths and weaknesses of the caregiver; 2) formal and informal support systems; and 3) commonalities amongst primary caregivers.

The decision as to where the patient would die was a difficult decision for many, but most were pleased with the decision that had been made. The results of this study would suggest a need for a palliative care program to be available at home as well as in hospital if all patients are to die with comfort and dignity.

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Finally a very special thank you to my family: my husband Cal, my children Lorelei and Jason and my parents Doreen and Elton Sharpe. Without their continued love and support this study could not have been conducted. Therefore, this study is dedicated to these people.

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Chapter I

STATEMENT OF THE PROBLEM

In the 19th century, dying and death were recognized as an integral part of the life cycle, and both the immediate and the extended family were closely involved (Blauner, 1966; Wald, Foster & Wald, 1980). In the 20th century, technology and medicine consistently redirected us away from the naturalness of the dying process, and at times even negated our right to participate actively in how we die (Hampe, 1975; Skorupka & Bohnet, 1982; Sobel, 1981).

In recent years there has been a surge of interest in the quality of care of the dying patient. This focus on the quality of life has led to the development of palliative care as an alternative model of care for the terminally ill patient.

Palliative care is defined in the Palliative Care Services in Hospitals Guidelines as follows:

"Palliative care" refers to the programs or services that provide care to those patients for whom treatment aimed at cure and prolongation of life is no longer appropriate but for whom therapy aimed at improving the

quality of the remaining life is the primary objective. Palliative care offers therapeutic services designed to address the physical, psychosocial and spiritual needs of dying patients and their families. (p.2)

The first decade of palliative care in Canada has witnessed a rapid increase in programs. Since the establishment in 1975 of palliative care units at the Royal Victoria Hospital in Montreal and St. Boniface Hospital in Winnipeg, there has been a rapid increase in the number of services and programs. Ley (1985) reports on a survey conducted by the Palliative Care Foundation which identified 116 Canadian programs with a total of 266 designated beds in operation by the end of 1983. Of the patients admitted to these programs, ninety-five percent were diagnosed as having terminal cancer. Although palliative care programs have undergone a surprising increase in the past decade only ten percent of the patients dying in Canada pass through a palliative care program (Ley, 1985).

The present trend both in the United Kingdom and in Canada is toward home care rather than hospice care. Hillier (1985) writes: "The argument runs like this: Hospice beds are expensive; home care teams are cheap: so replace hospices with home care teams"(p.13). In light of this trend, Hillier (1985) suggests an urgency for research on the Palliative Home Care Program in order to assure that the

terminally ill patient at home is able to die in comfort and with dignity. Greenley (1984) agrees that the home as a setting for care of the terminally ill requires study in order to assess its potential as a successful alternate to the hospital.

There is increasing evidence that most people would choose to die at home if appropriate supports were available (Ajemian & Mount, 1980; Bass, Pestello & Garland, 1984; Glaser & Straus, 1968; Kalish & Reynolds, 1976; Lack, 1980; Mor & Hiris, 1983; Parkes, 1985; Perrolaz & Mollica, 1981; Ross, 1981; Schmale, 1980; Skorupka & Bohnet, 1982; Tehan, 1983; Ward, 1978). Ajemian and Mount (1980) state, "The health care system should support, facilitate and assist the terminally ill in their desire to be at home while that is feasible and to die at home if that is possible" (p.19). Krant (1978) states, "The dying person should be allowed to finish his life at home, surrounded by a compassionate family, amid his own possessions and in a setting that can maximize psychological comfort" (p.546). "Since dying is the living we do at the end, people should be encouraged when possible to die the way they live" (Thompson, 1984, p.224).

The option for the dying patients to be cared for in their own home is being recognized increasingly by the general population and by health professionals (DuBois, 1980;

Greenley, 1984; Stoddard, 1978; Strauss & Glaser, 1975). The Task Force on the Allocation of Health Care Resources (1985) stated, "a compassionate coordinated program for the terminally ill, with an emphasis on the possibility of remaining at home, would be welcomed by consumers" (p.19). This Task Force (1985) also concluded that although some dying patients may prefer to be in a hospital, most would rather remain at home surrounded by their friends and family.

Throughout the literature there seems to be agreement that many family members, other consumers and the dying patients themselves would prefer to remain at home to die; yet statistics show that more than two thirds of Canadians die in institutions (Shephard, 1976). In Saskatchewan (Annual Report, 1982), 70.3 percent of the deaths occurred in hospitals. In the United States, Little (1985) reports that although four out of five people who responded to a recent study said they would prefer to die at home, current estimates showed that four out of five died in some institution.

As a result of the shift in hospice care from institutionally based programs to community based programs, dying at home may be possible for an increasing number of people. This trend was apparent in the Saskatoon Palliative Home Care program which began in 1984. At the end of the

first year, 75% of the clients were deceased and over half of them had died at home. The average client was sixty-five years old, diagnosed with cancer, and lived at home with a spouse as the primary caregiver (Evaluation of the Palliative Care Pilot Project, 1986).

With the increase in community palliative care programs, a great deal of the responsibility of caring for the terminally ill has been returned to the family. Few studies have looked at the impact of caring for the terminally ill person at home. Martinson and her colleagues (1977, 1978, 1986) have done a great deal in the area of care for the terminally ill child at home, but only a few studies (Barzelai, 1981; Rose, 1976; Wilkes, 1984) have looked at caring for the terminally ill adult at home.

From the author's personal experience in a Home Care program, it became apparent that many people were being sent home with a diagnosis of terminal cancer. In most cases, follow-up was to be provided through the family physician and the Home Care program. The question arose: How were the family and the patient going to cope with these last days of living at home? This situation had the potential for developing into a crisis for the patient and family alike depending on the resources that were available.

It also became apparent from clinical experience that one of the key people in determining whether a person returns home to die is the person who is designated as the primary caregiver. As was found in the Palliative Care program in Saskatoon, that person is generally a relative and most often tends to be the spouse (Evaluation of the Palliative Care Project, 1986). Librach (1985) expresses concern for those who are caring and coping with dying patients, concern rooted in fears for the adequacy of care given and concerns for emotional well-being that may be threatened by coping and caring for the dying patient.

The author also noted during clinical experience in a Home Care program that a great deal was expected of the primary caregiver by the patient, the health care professionals, the community, as well as from other family members. Many primary caregivers had had little experience in caring for a terminally ill patient and yet were expected to be able to cope physically and emotionally, while most of the attention is given to the patient. Malkin (1976) found that some families are unable to cope with caring for the terminally ill at home for more than a few days, while others were able to care for the patient until death occurred. Malkin (1976) found that for the families who were able to cope with the many difficulties, the emotional trauma is eased and the satisfactions were great.

To provide adequate support to the terminally ill patients and their families, it is essential for health care providers to understand how dying at home is perceived by families. The question asked in this study is: How do primary caregivers perceive their ability to care for the terminally ill family member at home?

Chapter II

CONCEPTUAL FRAMEWORK

2.1 Crisis Theory Model

The conceptual framework for this research is provided by the crisis theory model. This model includes the involvement of significant persons and an individual facing a hazardous event (Infante, 1982).

The concept of crisis as formulated by its chief theoreticians, Gerald Caplan and Erick Lindemann, was first developed as a psycho-social event. Caplan (1961) and Lindemann (1965) refer to crisis as a state of the reacting individual who finds him/her self in a hazardous situation. They emphasize that not all individuals faced by the same hazardous event will be in a state of crisis. On the other hand, they suggest that there are certain common hazardous events, such as loss by death and its sequel of grief and bereavement which will induce a state of crisis of lesser or greater intensity, or of lesser or greater duration, in nearly all individuals.

In its application, Caplan's crisis theory can be divided into three stages as depicted below: (Infante 1982, p. 14)

Crisis Theory Model

Stage I: Pre-Crisis

Dynamic Equilibrium
Man <--> Environment

Hazardous Event

Perception of Problem

Problem - Solving Mechanisms

Solution to Problem

----- or -----

Stage II: Crisis

Coping Mechanisms Fail + Stimulus

Additional Internal & External
Resources Mobilized Through Intervention

----- or -----

Stage III: Post-Crisis

Resolution of crisis / Growth of Health

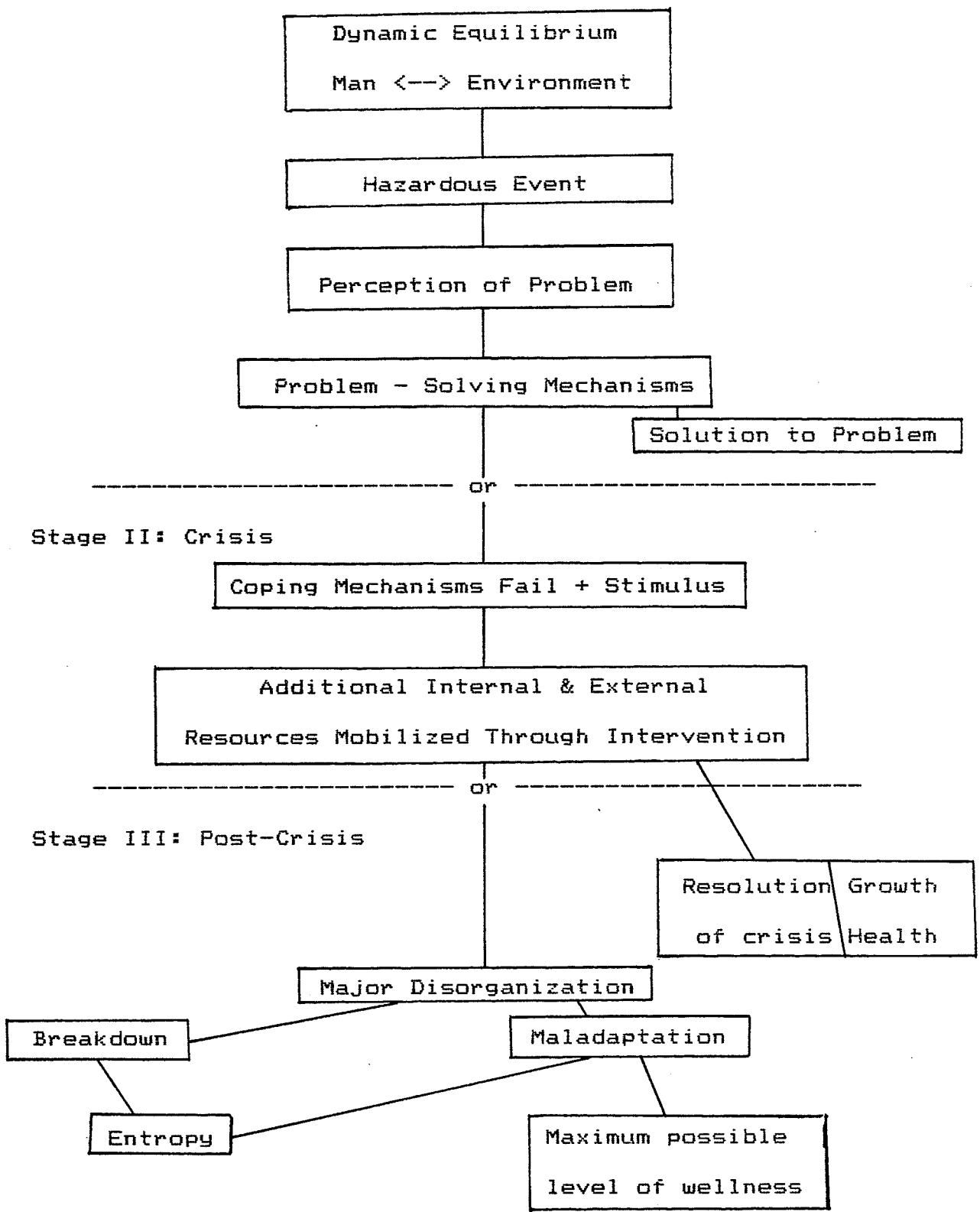
Major Disorganization

Breakdown

Maladaptation

Entropy

Maximum possible
level of wellness



2.2 Theoretical Definitions:

Dynamic equilibrium: a state of constant exchange, striving, action and reaction on the part of an individual. The person is viewed as existing in a state of interaction with the environment. Biological, psychological, social and spiritual factors combine to influence the state of dynamic equilibrium (Brownwell, 1984).

Hazardous event: an occurrence that has the potential for causing a state of disequilibrium. The hazardous event or occurrence may represent a threat (terminal illness), an actual loss (death of a loved one) or a challenge (providing care for a terminally ill family member at home).

Perception of problem: It is important to determine what the crisis means to the clients and how they feel it is likely to affect their future. When crisis occurs in a family some members see the situation differently from others. The person attempts to deal with problems or events from his/her point of view and reacts to them by calling upon problem solving mechanisms.

Problem Solving Mechanisms: People as living systems react in certain ways often unconsciously, in order to maintain relative equilibrium within themselves and in their

relations with others. Loss of homeostasis occurs when some internal or external force disrupts the system's balance and alters its functioning. In order to restore equilibrium people attempt to cope.

Solution to Problem: would include the quality of the individual's acceptance of the death (Quinn,1982); living life as fully as possible until the time of death; planning the circumstances for the death as close as possible to the wishes of those concerned; an atmosphere of dignity.

Crisis state: In a crisis, the problem is generally unfamiliar and greater than usual. The critical factor influencing the occurrence of a crisis is an imbalance between the importance and difficulty of a problem and the resources available to deal with it (Caplan,1964). Learning of the diagnosis of terminal illness in a family member, along with caring for that family member and preparing for the death of that person may all be events which could lead to a crisis for the caregiver, other family members and for the patients themselves. Other situations which may lead to crisis during the final stages of a terminal illness are incontinence, increased pain, choking and role changes. In the state of crisis, the individual usually reaches out to seek and utilize the resources of his community.

A system's strong need to regain homeostasis means that the disequilibrium of a crisis tends to be self-limiting

lasting four to six weeks (Caplan, 1961). The urgency of the situation and its time limitations require the prompt, focused attention of clients and health professionals working together to achieve a successful outcome.

Coping Mechanisms Fail + Stimulus: If their efforts fail to solve the problem, feelings of anxiety and inadequacy increase. Aguilera and Messick (1986) suggest that a person in this situation feels helpless, is caught in a state of great emotional upset and feels unable to take action on their own to solve the problem. At this point the person is not self supporting and external intervention is needed.

Additional Internal & External Resources Mobilized Through Intervention: The primary goal of crisis intervention is to reestablish equilibrium, to help the family through the crisis while allowing them autonomy (Christensen & Harding, 1985). The role of the intervenor is to assist the person in crisis extend personal resources. This may then effect satisfactory resolution of the crisis and achieve growth (Infante, 1982).

Resolution of crisis: refers to the success of the intervention. The individual learns new coping mechanisms, resulting in growth. Growth occurs when we mature in the crisis and develop more effective ways of dealing with problems. "Those who engage in healthy adaptation during a

crisis will emerge unharmed, even strengthened. They have become prepared to cope with similar events in the future" (Spradley, 1985, p.316).

Major Disorganization: results if the crisis is not resolved. "It becomes more difficult to mobilize resources or even to seek and make optimal use of additional available help. Growth is less likely to occur"(Infante, 1982, p.20). If the problem continues unsolved (or avoided) the breaking point is reached.

Maladaptation: suggests a lower level of functioning than previously existed. "Since compensatory processes within the body are usually evoked, the aim is to lead the individual to a maximum possible level of wellness" (Infante, 1982, p20). Moreover, maladaptation can result in a very low level of functioning and can eventually lead to entropy.

Breakdown: complete emotional breakdown means total disorganization, which would result in little if any function. Breakdown leads to entropy.

Entropy: diminished capacity for spontaneous change. Entropy is a loss of energy that can occur suddenly or over a period of time. In the context of crisis theory, entropy leads to death (Infante, 1982).

Chapter III

REVIEW OF THE LITERATURE

3.1 Introduction:

A review of the literature related to crisis theory and caring for the dying at home resulted in the identification of several concepts. Crisis and crisis theory were reviewed in relation to the effects on the primary caregiver when caring for the dying patient at home. The concept of family was also reviewed since the primary caregiver at home was found to be generally a family member. Another concept which was found to be closely related to caring for the terminally ill at home was that of coping. Coping is also a major factor in dealing with a hazardous event and the resolution of crisis. The final area to be reviewed was that of dying at home and what it means to the primary caregiver.

3.2 Crisis and Crisis Theory:

The term "crisis" has a variety of meanings depending on how it is used. In lay language, a crisis is usually equated with disaster, an environmental event which poses

external threat (Rapoport, 1965). Erikson (1963) and others talk of developmental crises which are induced by the special tasks required by each new developmental phase in the sequence of psychosocial maturation. As well, crises and stress are often used interchangeably. The concept of stress tends to carry a negative connotation referring to burden or load under which a person survives or cracks. In contrast, a state of crisis is conceived to have a growth promoting potential.

Parad and Caplan (1965) define crisis as "the impact of any event that challenges the assumed state and forces the individual to change his view of, or readapt to, the world, to himself or both" (p.56). Crisis can occur with any change in which the demands are greater than the resources.

In the Chinese language, the word "crisis" consists of two characters, one a symbol for "danger", the other a symbol for "opportunity" (Infante, 1985). In both situations, where danger is perceived or opportunity is perceived, the potential for growth on the part of the individual exists. If the resources or problem-solving mechanisms available to the individual are sufficient in number and type, as well as effectiveness, the individual is likely to experience growth.

Crises can be classified into two main types: maturational and situational. Maturational crises deal with the developmental tasks of individuals. The hazards created by these tasks are common to all people, and many people go through these events without incurring a crisis. Situational crises are usually the result of some occurrence usually beyond the individual's or family's control. The event cannot be prepared for, as it cannot be predicted.

The diagnosis of cancer, especially when sudden or unexpected, has the potential to develop into a crisis for the individual and the family (Anthony, 1970; Giaquinta, 1979; Gray-Price & Szczesny, 1985; Lev, 1985; Rose, 1976; Strauss & Glaser, 1975; Welch, 1981; Winder & Elam, 1978). Goldberg (1974) suggests there are two characteristics of death as a stress event which make it readily convertible into a crisis situation. The first is its stark finality - the irretrievable loss of a human being. The second is that, because death is not a frequent occurrence, one usually has little experience in dealing with it and, therefore, needs to seek a novel solution when it occurs. "The family's resources may mitigate the severity but will not necessarily prevent death from being perceived as a crisis" (Goldberg, 1974, p. 21).

A model of crisis theory and intervention provides a view of the diagnosis of terminal cancer as a hazardous

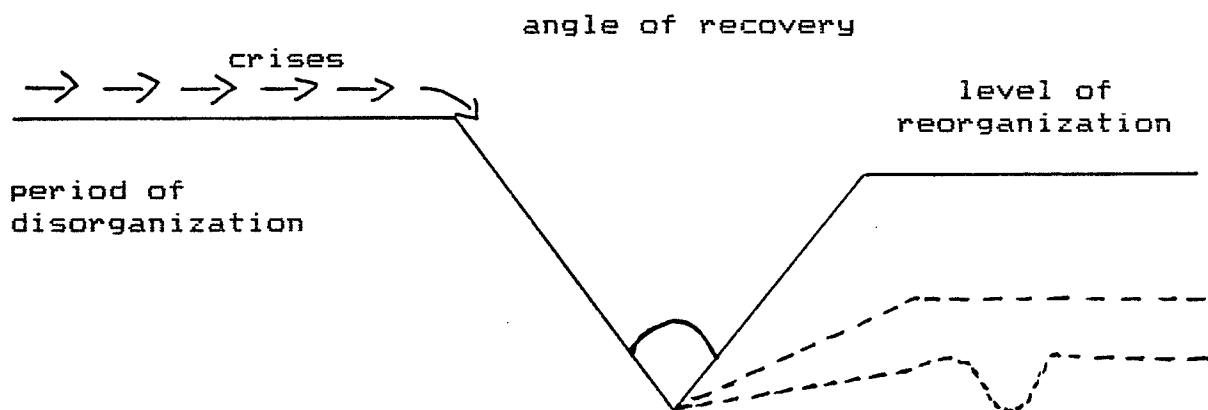
event which has the potential for becoming a situational crisis. The nature and resolution of such an event is dependent on the factors identified in crisis theory. Rapoport (1965) suggests that many individuals are able to develop new solutions by means of the normal range of problem-solving mechanisms stemming from their life experiences and maturation, and are thereby able to deal adequately with the hazardous event. Others are unable to respond with the appropriate solutions, and the hazardous event and its sequelae continue to be a source of stress.

Aguilera & Messick (1986) provide a paradigm for crisis intervention that delineates three balancing factors that must be present (if a crisis is to be avoided) when a stressful event disrupts the homeostasis. These balancing factors are: a realistic perception of the event, adequate situational support and adequate coping mechanisms. Should any of these balancing factors be absent they predict a crisis will result.

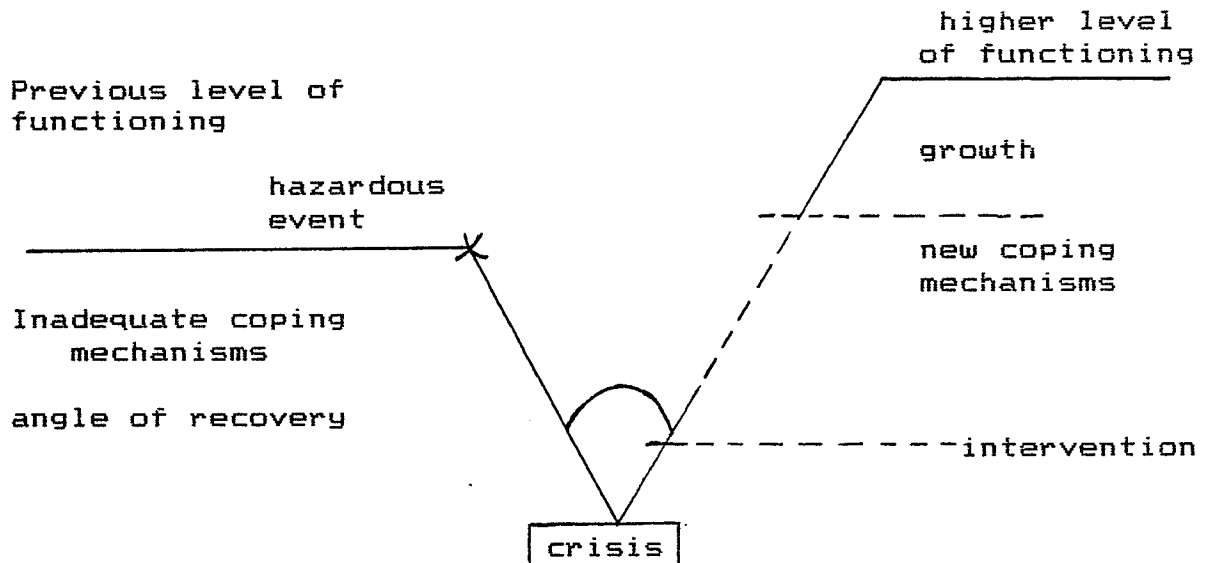
According to Caplan (1964), the essential factor influencing the occurrence of a crisis and the ability to cope with it is the resources available to deal with the crisis. Lev (1985) suggests, "The help or hindrance received by others - professional caregivers as well as friends, family and community supports - may make the difference between acceptable adaptation and maladaptation to the situation" (p.72).

Caplan (1965) states that a person cannot remain in a state of disequilibrium for more than six weeks. During that time the crisis is successfully resolved with intervention, or else major disorganization occurs. Successful intervention in a crisis leads to reorganization and attainment of a higher level of growth and wellness, because new strategies and resources are introduced into the individual's repertoire of responses for coping with future hazardous events. If the crisis is not resolved, the individual may fall to a level of wellness lower than that of the pre-crisis stage. This maladaptation may take the form of a chronic physical or mental disorder, or it may lead to complete breakdown and death.

Hill (1966) viewed the course of adjustment to a family crisis in the profile of a roller-coaster. The component parts to the roller-coaster profile of adjustment are: crises -> disorganization -> recovery -> reorganization as designed below: (p.46).



Infante (1982,p.19) developed this model further as below:



The "X" marks the entry of a hazardous event with a period of disorganization following. When the problem-solving mechanisms of the individual fail, the individual plunges into crisis. Internal and external resources are called into play to assist in a healthy resolution. The angle of recovery is dependent upon the timing and the appropriateness of the interventions. The new dynamic equilibrium may be better or worse than formerly existed.

3.3 Family:

"There is no uniform or universally accepted definition of the family, due to cultural differences in function and structure, and due to various approaches taken by the many disciplines that study the family" (Thibodeau & Hawkins, 1982, p.81). Thibodeau & Hawkins (1982) suggest that the family may refer to a two-parent unit with or without children, a single-parent unit, or groups of related or unrelated persons sharing a household.

The family is traditionally viewed as the first line of defence to support one of its members who faces a crisis (Giacquinta, 1977). The family is a social system whose structure is founded on a contracted network of interactions and obligations (Dow, 1965). Therefore, the impairment of any family role will require the alterations of reciprocal roles (Infante, 1982; Kalish, 1981; Sobel, 1981; Welch, 1981) with the likelihood of increasing familial stress and crisis. "The diagnosis of terminal illness in a family member hurls the family into an acute crisis situation, disrupting normal patterns of interaction and behavior" (Cohen & Cohen, 1981, p.177). The living - dying phase is described as a "physical and psychosocial limbo" for the family (Cohen & Wellisch, 1978). Normal plans are suspended and routine functions are interrupted as the family searches for a new equilibrium in the face of impending death.

Because of the implications for disruption to family functioning, the family should not be viewed solely as the principle refuge for the sick but rather as a unit facing crisis and, therefore, the target of nursing care (Craven & Wald, 1975; Giaquinta, 1977; Infante, 1982). This is felt to be especially true if the family unit is expected to mobilize resources and care for the patient in a home setting. The question arises: How can the family members be expected to provide the patient with the necessary emotional support, carry out nursing care, and maintain their own psychosocial integrity and relationships when they themselves are facing a hazardous event which has the potential for developing into a crisis situation?

Spouses, children, parents and extended family members experience both psychological and physiological health changes in response to the stress of a terminal illness in the family (Cassileth & Hamilton, 1979; Degner, Beaton & Glass, 1981; Klein, Dean & Bogdonoff, 1967; Kristjanson, 1983). Kristjanson (1983) reported that family members experienced exacerbations of chronic illnesses such as diabetes, hypertension and ulcerative colitis during the illness episode of a spouse with cancer. Weisman (1962) also observed that not only were so-called psychosomatic illnesses very common in survivors, but the onset of various unquestionable organic diseases could be traced to such psychosocial events as bereavement, depression and despair.

Other clinical studies (Bowen, 1976; Dohrenwend, 1973; Holmes & Rahe, 1967; Raphael, 1977; Strauss & Glaser, 1975) indicate family members are at high risk for emotional difficulties following the loss of a loved one. Such findings underscore the importance of extending our concern for the dying person to include the entire family system.

Families' habitual problem - solving styles are automatically used while attempting to cope with the trauma of terminal illness. The response to a terminal illness is seen not as a singular, unilevel and unprecedented reaction in the life of a family, but rather as a derivation of the customary patterns of problem resolution (Berkun, Bialek, Kern & Yagi, 1962; Cohen & Cohen, 1981). MacVicar & Archbold (1976) point out that, "The vulnerability of the family unit to a crisis event such as illness is related to the ability of the family members to modify their respective roles, perform tasks essential for the continuity of family life and redefine personal expectations and goals" (p.183).

The habitual problem - solving mechanisms may or may not adequately or effectively lead to the previously achieved state. If the resources or problem - solving mechanisms called into play to handle a given situation are sufficient in number and type, as well as effective, the

individual is likely to experience growth. Cobb (1976) agrees that social support networks available to families coping with crisis are crucial determinants in the facilitation of effective coping. "One major cause of a client going into a crisis is the failure of his old coping patterns that have supported his needs in the past to resolve the new hazardous event with which he is faced" (Moynihan & Hayes, 1982, p. 644).

Clemen et al. (1981) suggest several factors that influence how a client perceives a crisis:

1. Number of stressors client is experiencing.
2. Client's past experiences in handling current stressor(s).
3. Biopsychosocial status of the client prior to encountering hazardous event(s).
4. Duration of exposure to current stressor(s).
5. Magnitude or seriousness of current event(s).
6. Suddenness of the event.
7. Client's understanding of the stressor event(s)
(p. 181).

Individuals may view the situation or the hazardous event as a challenge, a threat or a loss (Infante, 1982). Their view depends on their physical and emotional state as well as the repertoire of resources

available to them. If the family is stable, it can absorb the individual crisis and be supportive. If the family has limited resources, then the individual crisis may increase the family's inability to cope with the family or individual crises leading to breakdown of the family as well as the individual (Moynihan & Hayes, 1982,p.646).

It has long been recognized that people need meaningful human relationships in order to cope with the stresses of life. Significant others (family, friends, relatives, professionals and others) can increase or decrease an individual's vulnerability to crisis during times of stress. During periods of disequilibrium, persons need supportive relationships to allow them to verbalize feelings and encourage them to sort out the realities of their situation (Clemen et al, 1981). Fromer (1979), suggests that the cultural and social background of the family and the individual, as well as previous experience with illness (their own and that of people they know) can affect the way they react.

Patterson and McCubbin (1983) view coping as the family's ability to acquire and use the resources needed for family adaptation. These resources may be developed from within the family boundaries, such as cohesiveness by pulling together to meet the demands of home care for the terminally ill patient. In addition, the family's resources

may be acquired from outside the family, such as securing competent medical services in the community, or social support from other families experiencing the same hazardous event.

Hill (in Fromer, 1979), in research on black families, identified five characteristics that are indicative of family strength:

1. A concern for family unity, loyalty, and interfamily and intrafamily cooperation.
2. An ability for self-help and the ability to accept help when appropriate.
3. An ability to perform family roles flexibly.
4. An ability to establish and maintain growth-producing relationships.
5. The ability to provide for the physical, emotional and spiritual needs of the family (p.300).

The greater the abundance of these qualities and the more highly developed they are, the greater the family's ability to cope with the illness and the individual and to be of some constructive and positive help to him.

Another important factor to be considered when planning care for the terminally ill patient and his/her

family is to allow them control. In order to have quality of life until death, the patient must maintain as much control as possible (Quinn, 1982; Selegman, 1975, Skorupka & Bohnet, 1982). For many terminally ill persons, the need for control becomes an adaptive coping mechanism as they struggle with an illness over which they have little or no control (Ajemian & Balfour, 1982). A prime consideration in providing care to the terminally ill is to allow both the patient and his/her family to control situations and outcomes and to be participants in the patient's care plan if they so desire (Degner et al., 1981; Kristjanson, 1983; Skorupka & Bohnet, 1982).

Averill (1973) provides a detailed review of the relationship between perceived stress and perceived control and concludes that it's not the form of control one has over events that matters, but rather it is the symbolic significance that one has some control at all. Glaser and Strauss (1968) identify this need for an internal locus of control as being one of the most common characteristics of people who decide to either die at home or to remain at home as long as possible before death occurs. Home care is an aspect of health care which aims to keep patients in control of their own lives as much and for as long as possible (Rossman, 1979).

Williams (1978) suggests that when patients are nursed at home, a careful study has to be made of the factors most needing alleviation in the opinion of the helpers. Failure to recognize these can produce undue strain on families and although basic care may still be present, crisis may be imminent and urgent action is often necessary to support these helpers. Williams views a preventive approach as being very important if such problems and crisis are to be avoided. It is most important that health care professionals see that the care given is appropriate to the needs of the terminally ill patient and their family.

3.4 Coping:

Coping has been defined in different ways by different authors. It has been defined by Lazarus and his associates as the efforts, both action oriented and intrapsychic, which an individual makes to manage environmental and internal demands which tax or exceed personal resources (Lazarus & Launier, 1978). Monat and Lazarus (1977) state, "Coping refers to efforts to master conditions of harm, threat or challenge when a routine or automatic response is not readily available" (p.8).

Unlike Lazarus, Weisman and Worden (1976-77) differentiate between coping and defending. According to them, coping involves the individual taking active measures

which result in mastery, control or resolution of an identified problem and as a consequence, relief of distress. Weisman and Worden (1976-77) believe that the individual faced with an identified problem responds with a coping strategy. The coping strategy employed either does or does not lead to a resolution of the problem. If the problem is resolved the individual will have coped effectively with it (Weisman & Worden, 1976-77). According to this definition of coping, individuals should be able to identify the problems they are facing, the coping strategies they have used and the extent to which the problems have been resolved.

Lazarus (1966) suggests that when we use the term "coping" we are referring to strategies for dealing with threat and crises. Murphy and her colleagues have used the term "coping" in their analysis of the way young children meet some of the demands and crises in their lives. Murphy (1962) writes:

It is possible that by watching them (children), we may learn something about how all of us deal with new demands and stressful experiences, newness which cannot be met by well-established habits of ready-made answers. When responses are not automatic, when we do not know just what to do, we have to cope with the situation as best we can, trying to arrive at a solution that will enable us to get along. Much of what

we call "getting experience" consists of just this, and out of these efforts to cope with new situations eventually develops a certain know-how, patterned ways of dealing with newness itself (p.1-2).

Mengel (1982) states: "Coping is now viewed as a phenomenon with biological, psychological and social variables. It is seen as a set of behaviors -conscious or unconscious - that a person adopts when facing stress" (p.1). Mengel believes this concept of coping to be consistent with the philosophy of holistic health care. Holistic health care provides a way of dealing with life's changes by emphasizing coping through increased self-responsibility and participation in the change process.

Mengel (1982) views effective coping as a dynamic process in which biological, psychological and social resources are mobilized. The selection of which personal resources to mobilize and under what conditions is complex and is not fully understood. The question remains: Why is one person better able to cope than another?

Ziemer (1982) concluded from her review of the literature related to coping, that it is in the interest of science that the concept of coping be better understood. At the present time she found there were no adequate methods

for measuring the concept of coping. The need for further study of the nature and substance of people's coping repertoires in everyday life situations and the relative effectiveness of different ways of coping has been repeatedly cited (Kanner, Coyne, Schafer & Lazarus, 1981; Mechanic, 1974; Pearlin & Schooler, 1978). Such investigations are seen as necessary in order to provide information about effective strategies for avoiding or reducing stress in order to assist people to attain or maintain high levels of wellness.

Lazarus and his associate (Roskies & Lazarus, 1980) believe that coping behavior can be evaluated along two dimensions: a) the effectiveness with which a task is accomplished and b) the cost of this effectiveness to the individual. The cost to the individual can be separated into two components: a) the physiological cost of harmful disturbance in body homeostasis, and b) the psychic cost of violation of value integrity. Thus coping behavior may be said to be effective when a task is accomplished according to standards tolerable to the individual and the group in which he lives. Lazarus (1981) believes that coping effectiveness can only be judged by outcome in morale, social functioning and somatic health.

Throughout the literature on "coping", there is reference to the importance of age, sex, religion, ethnic,

health and socioeconomic variables such as income, occupation and education (Bateson, 1968; Bryne & Thompson, 1978; Crosby & Jose, 1983; Infante, 1982; McGrory, 1978; Moynihan & Hayes, 1982; Quinn, 1982).

Lazarus and Folkman (1984) suggest that people with money, especially if they have the skills to use it effectively, generally fare much better than those without money. Simply having money, even if it is not drawn upon, may reduce the person's vulnerability to threat and may also facilitate effective coping. Hill (1965) also referred to several studies that offered evidence that families whose economic well-being is marginal are more vulnerable to crisis.

Ross (1981) suggests that people are shaped by the cultural values of the ethnic, religious and social segment of society in which they were raised. He refers to the Amish Community where a deep religious faith and strong emotional ties contribute to a calm acceptance of death. Ross (1981) states, "Open discussion of death, care of dying family members at home and a high ceremonial emphasis on the death event help the Amish people to cope with impending loss" (p.9).

Buchanan (1984) suggests that when religion provides individuals with the beliefs that they have the ability to

cope, that there are extrapersonal reserves of strength, that it is possible for some small good to come from the present situation, then religion will facilitate the resolution of stress and an overall healthy adjustment.

In every culture, there are attempts to explain the meaning of existence (Fong, 1985; Reinhardt & Quinn, 1973; Shelton, 1981). Attitudes toward death should not be viewed as isolated phenomena but as attributes related to experience. Fong (1985) states, "Nurses must appreciate a patient's unique ethnic identity and his or her ability to adapt in health, crisis and illness" (p.9).

Perception of a stressful event is viewed as playing a major role in determining both the nature and degree of coping behaviors (Aguilera & Messick, 1986; Quinn, 1982; Venters, 1980). Aguilera & Messick (1986) suggest there are three recognized balancing factors that may determine the equilibrium between the perceived effects of a stressful situation and the resolution of the problem. These factors are: the perception of the event, available situational supports and coping mechanisms. Situational supports refer to those persons who are available in the environment and who can be depended upon to help solve the problem. Aguilera & Messick (1986) believe that strengths and weaknesses in any one of the factors can be directly related to the onset of crisis or its resolution.

Lazarus (1966) suggests that when a threatening situation exists, a primary appraisal is made to judge the perceived outcome of the event in relation to one's future goals and values. Then a secondary appraisal follows whereby one perceives the range of coping alternatives available either to master the threat or to achieve a beneficial outcome. As coping activities are initiated, feedback is received from the internal and external environments leading to ongoing reappraisals or to changes in the original perception.

Meaningful relationships with others provide a person with nurturance and support, resources vital for coping with a wide variety of stressors. When a person lacks these meaningful relationships they are much more vulnerable when confronted with a possible crisis (Lazarus, 1966). Hill (1965) found that families that best succeeded in meeting a crisis of war-time separation made frequent mention of accessibility of relatives, neighbors and friends. Rarely did they mention the churches, family agencies or other welfare groups that claim they provide services of this kind to families in trouble.

The quality of crisis resolution in part depends on interactions among sources of care and support within and without the family. The health care system is one of these sources. In varying degrees health care workers are directly

and indirectly involved in the family's living-with cancer experience; thus the type and quality of health care provided become important variables that affect crises resolutions as well as the family's relationships within a network that will assist them over time in coping with cancer. If the primary caregiver is to respond constructively to the crises of diagnosis of terminal cancer in a family member, and is to develop effective coping maneuvers that serve them well during the course of caring for the terminally ill person at home, effective collaboration and coordination among facets of their entire network - including the health care system - must take place.

Figley (1983) outlines eleven universal characteristics which differentiate functional and dysfunctional coping.

1. ability to identify the stressor;
2. viewing the situation as a family problem, rather than merely a problem of one or two of its members;
3. adapting a solution - oriented approach to the problem, rather than simply blaming;
4. showing tolerance for other family members;
5. clear expression of commitment to and affection for other family members;
6. open and clear communication among members;

7. evidence of high level cohesion;
8. evidence of considerable role flexibility;
9. appropriate utilization of resources inside and outside the family;
10. lack of overt and covert physical violence;
11. lack of substance abuse.

Figley (1983), following a review of family reactions during catastrophes, concluded that family is the single most important resource in dealing with catastrophic stress. Catastrophe is defined by Figley as an event which is sudden, unexpected, and often life-threatening (to us or someone we care deeply about), and due to circumstances renders the survivors feeling an extreme sense of helplessness. "By adequate attention to the health and vitality of the family system, victims of catastrophe may rely on a powerful stress-coping resource" (Figley, 1983, p.20).

In relation to crisis theory, how individuals are able to cope in a pre-crisis or crisis situation is important to their outcome. "Some seek out the help they need and come through the experience unscathed, perhaps even stronger than before. Others, unable to cope, incur severe, sometimes permanent, damage" (Spradely, 1985, p.312).

3.5 Dying at home:

"The care of the dying demands all that we can do to enable patients to live until they die. It includes the care of the family, the mind and the spirit as well as care of the body" (Saunders, 1983,p.7).

Noyes and Clancy (1983) view society as failing to meet the obligation it has to its dying members. Persons with terminal illness suffer isolation and neglect in hospitals, receive over - zealous treatment by physicians, and are kept in ignorance of their situation by families and medical personnel. Evidence for these statements has come from observers of the medical care system and from dying patients themselves (Kubler - Ross, 1969; Reynolds & Kalish, 1974; Sudnow, 1967).

Although most people will state that they would prefer to die at home (Kalish & Reynolds, 1976), the assumption is often made that the hospital is the "proper" place to die. Most people in the United States, Canada, England and most European nations die in hospitals (Hinton, 1979; Lerner, 1970). Kalish (1981) states "Since a hospital or other institution is still perceived as the "natural" place to die, many people don't even consider the alternative of dying at home" (p.267).

Cockburn (1983) sees Hospice/Palliative Care as caring for individuals in as homelike an atmosphere as possible; therefore it should be seen as helping families continue as long as possible in giving care at home for those who are able and wish to do so. The hospice concept promotes 24-hour availability of supportive services, not necessarily 24-hour presence of supportive services. In the absence of such support, family members are expected to cope with the patient care management skills necessary to provide care for the terminally ill patient. Grobe, Ilstrup and Ahmann (1981) suggest that a great deal of the success of existing palliative home care programs has been attributed to the willingness of family members to manage the patient's care.

Kalish (1981) views caring for someone you love who is dying as one of the most demanding and often one of the most rewarding relationships that one can enter. He sees the person who provides the greatest amount of care as being in a unique situation. This caring often results in a full time job with many demands ranging from changing the dying person's bedding, to giving a bath, to sitting silently and holding hands, to talking about funerals and cemeteries. As the person's condition worsens, the demands for attention and involvement can be expected to increase. At this point some people choose to transfer the dying to an institution or hire someone to provide care at home while others, who want the dying to be able to die at home, face the tasks that are continual, difficult and emotionally draining.

Kalish (1981) suggests that the primary caregiver may come to resent his or her involvement, feel that others in the family are not helping enough or that the sacrifices made to provide the care - such as leaving a job, relocating from another community, or requiring younger children to become self-sufficient - are high prices to pay. Given that some tension and resentment might enter the relationship, the primary caregivers may first feel angry and then guilty over the anger and over the feeling that they could have done better.

One question which remained unanswered for Kalish (1981) was: Who is taking care of the primary caregiver? Other questions were: Is there enough sustenance from the primary caregiver role to provide the primary caregiver with a sense of well being? Are there others in the primary caregiver's life who can provide the emotional support that is needed to endure both the physical fatigue and the emotional pain which is experienced? "It is important, as we turn more and more attention to caring for persons who are dying and those who are grieving, that we don't ignore or turn into "villains" those who, either as professionals or as family members, are doing their best to provide physical and emotional care and support" (Kalish, 1981, p.304).

Although much attention has been given to the need for patient education directed at self-care and health promotion (Chaisson, 1980; Hussar, 1979; Orem, 1980), the literature is sparse with respect to learning needs of family members involved in the care of the terminally ill patient. Cockburn (1983) noted that success of home care is based on good symptom control, and that often it is just fear of the unknown that inhibits the family from caring for the patients in their own environment.

The fact that most individuals die in hospitals rather than at home as in previous generations, has denied family members the opportunity to come face to face with death. Quinn (1982) believes this has also prevented them from learning to communicate, learning to provide support, and becoming more comfortable and insightful with the dying and with death itself.

It is now recognized that those who care for the dying patient frequently experience considerable stress and that ways of helping them cope need to be developed (Vachon, 1978; Vachon, Lyall & Freeman, 1978). One of the basic concepts in current stress theory is that the individual has a finite amount of energy for adapting to stressful situations, and unless this energy is replenished regularly, the supply becomes exhausted (Selye, 1956). Vachon (1983) warns that those who work with the dying are particularly at

risk of depleting the energy they have to give, because of the tremendous emotional investment such work entails.

Martocchio (1982) found the literature to be replete with studies of pain and pain management, as well as advice about the needs of patients, caregivers and family members. "Yet, the problems and dilemmas associated with dying and death seem at times insurmountable" (p.138). As a result of other studies as well as her own, Martocchio (1982) found there is a need for more understanding of the realities involved in living while dying. She believes attempts to understand and cope with the realities of living while dying are doomed to failure unless societal attitudes and the interactional settings are taken into consideration. Interactional settings refer to the particular environment of care such as the home, hospital or hospice, as well as the individual characteristics, capabilities, and attitudes of all the interactors, be they the dying person, family members, caregiver or others.

Martocchio (1982) does not consider focusing on the needs, hopes, fears and desires of people living with their dying to be sufficient, since the dying experience involves all persons in the interactional setting. Each individual in the situation copes with dying or deals with the situation in his or her own way. Yet, each is influenced by the actions and reactions of the other. Thus, the realities of

living while dying cannot be understood or successfully addressed if the focus is exclusively on the person who is dying without considering the total situation and setting.

Martinson's research (1977,1978,1986) with children dying of cancer begins to address the concerns parents have in managing a child's care at home, but little has been documented about the needs of families of adult patients who face inevitable death. Martinson (1978) found that for the dying child, for whom any substantial medical help is no longer possible, the home may be the more appropriate setting. She found evidence that when there has been adequate preparation of the child's family and when there is a support system available to the parents, they are able to provide quality care for the child.

She also found that the emotional and psychological benefits to the child and his family were great. Most of the parents who experienced home care felt the grief process was eased considerably by knowing that they were with their dying child when their child needed them most, and that they had the opportunity to do all within their power to help him/her through the crisis.

A study by Barzelai (1981) involved twenty subjects consisting of significant others who had participated in the hospice program. Significant others referred to the relative

or friend closest to the dying person, who tended to the dying person and acted as a liason between the patient and hospice. Eighty-five percent of the respondents said it was desireable for a dying person to be at home as much as possible. Reasons given were: the patient was more comfortable; it enabled the family to grow closer together; it enabled the patient to have some control over his life; and, it enhanced the patient's will to live.

Rose (1976) interviewed twenty-six family members of adult cancer patients who had lived at home sometime during the eight weeks preceeding their deaths. Most families reported that the patient's physical needs - such as bathing, feeding, and dressing changes - were met by immediate relatives or close friends. Only one of the twenty-six families reported that they had had visiting nurse assistance. Sixteen family members reported that they needed some type of special equipment to lighten the burden of the patient's physical care, but only eight said they obtained what they needed.

Nineteen families indicated a need for teaching about home care, particularly in those areas requiring greater knowledge and judgement, such as pain control or special foods. Almost all families reported that while the patient was at home, problems arose which they believed required a doctor's assistance. Fourteen families said that medical

attention was inadequate. Thirteen of the twenty-six family members mentioned problems in getting the patient to and from the hospital or clinic for treatment. Other problems identified were sleep, finances, and child care.

Wilkes (1984), in a study using a random sample of 262 deaths, interviewed the family caregivers one to six months following the death. He found the difficulties of the relatives were more often the reason for hospital admission than the needs of the patients. The main reasons for admitting the patient to hospital according to the relatives were; better care was available there (41%), relative felt physically unable to cope (26%) and relative felt emotionally unable to cope (19%).

In retrospect, Wilkes (1984) found that 7% of the relatives of patients who died in hospital would have preferred that the death occur at home and only 3% of the relatives of patients who died at home would have preferred that the death occur in hospital. Important anxieties which were identified in home care were the difficulties in getting any trusted, familiar out-of-hours advice, and delays of up to four or even eight weeks in obtaining basic equipment such as incontinence pads or commodes.

Bass, Postello and Garland (1984) also found evidence that indicated patients and caregivers who have more

difficulty with terminal care at home are more likely to return to a facility. Kalish (1965) reports that the location of patients when they die is an outcome measure reflecting the experiences of patients, families, and caregivers. More specifically, the place of death reflects both the degree to which caregivers experience difficulties with providing care at home, and whether home hospice care provided patients with an ideology and set of services which satisfied their needs (Kalish & Reynolds, 1976).

During the past five years family members have become recognized within the long term care system as being the major care providers for impaired adults. Because of the recognized importance of the family caregiver in the long term care system, research is now being done to better understand the distribution, correlates, and consequences of caregiving (Gwyther & George, 1986). Gwyther and George (1986) indicate that caregiver functioning and perhaps institutional placement is better predicted by characteristics of caregivers and caregiving context than by illness characteristics.

As a result of the findings, Gwyther & George (1986) suggest that service providers and clinicians look beyond the objective functional status of the patient in order to adequately support caregivers and enhance their effectiveness. "Indeed, these findings suggest that caregiver well-being cannot be understood without a broad

view of the caregivers' subjective perceptions, personal characteristics, and social resources" (Gwyther & George, 1986, p.247).

Zarit, Todd and Zarit (1986) suggest an important issue in research on caregivers is their variability - how they differ from one another in their response to caregiving demands. Clinical observations indicate that some are quickly and decisively overwhelmed, and others make quiet, stubborn efforts to care for their relative at home. Research that identifies sources of this variability could be useful in planning programs that reduce the stress on family members and prevent premature or unnecessary institutionalization.

Shneidman (1980) found that from the relative's point of view nursing someone at home could be a severe stress; however, there is reason to believe that in the long term, people who have cared for someone in this way may find themselves coping with life better after bereavement. Most studies about death tend to ignore the fact that the problems of loss and grief begin before the loved one's death, that there is anticipatory grief which follows notification of an unfavorable prognosis (Hampe, 1975). Kubler - Ross (1970) maintained that if widowed persons had been helped before the death of their partner to bridge the gulf between themselves and the dying one, half of their battle to work through guilt and grief might have been won.

Hampe (1975) suggests that the family's involvement in the physical care of the dying person is extremely important in allowing the family members to feel that they have done something significant for the person and in relieving guilt to some degree. When family members are able to observe and participate in the care of the loved one, they are given the opportunity to give and receive satisfaction in the remaining time allowed the relationship.

Kalish (1977) suggests there are forms of compensation when caring for the terminally ill. The primary caregivers at home are able to control information, the physical space, and the emotional contacts with the dying person. They can decide who visits and when, who is privy to what information, and what messages are carried. Kalish (1977) suggests that after the death, this person may find adjustment the most difficult in terms of reestablishing social cultures, work career, or organizational involvement, but will probably have the least guilt and the fewest feelings of having unfinished business of anyone in the family.

Rees and Lutkins (1967) conducted a survey to assess the effect of bereavement on the mortality of close relatives in a small semirural community (371 who died were compared to a control group). It was found that 4.76% of bereaved close relatives died within one year of bereavement

compared with 0.68% in the control group. They also found that if the first relative dies in hospital the bereaved close relatives carry twice the risk of dying within a year of bereavement than if the first relative had died at home. This increase in the risk for bereaved close relatives when the original death occurred in hospital compared with at home was significant at the .05 level.

3.6 Summary and Conclusion:

As a result of the literature review, several factors contributed to the need for the study: a) concern about the quality of care provided for the terminally ill patients and their families, b) the fact that most terminally ill patients wish to remain at home as long as possible, c) the trend toward more terminally ill patients being cared for at home, d) concern for the family caregiver while caring for a terminally ill family member at home, e) the fact that many questions still remain unanswered due to the lack of research in the area of the role of the caregiver while caring for a terminally ill family member at home.

The need for further research in this area became evident as a result of the literature review. There was also a sense of urgency related to further research because of the present trends. A descriptive - exploratory study was designed to better understand the role of the primary caregiver and to provide a basis for further research.

Chapter IV

RESEARCH DESIGN and METHODOLOGY

4.1 Purpose of the Study:

The purpose of this study was to gain a better understanding of primary caregivers and how they were able to manage the care of a terminally ill adult family member at home. Specific objectives were:

1. To identify the primary caregiver's self perceived strengths and weaknesses.
2. To identify the reported key factors, including formal and informal support systems, which were influential in the primary caregiver's ability to care for the terminally ill person at home.
3. To determine whether commonalities exist among primary caregivers who are able to care for the terminally ill patient at home.

4.2 Functional Definitions:

1. Primary caregiver - that person identified by the Palliative Home Care staff or self, as the one principally responsible for providing and coordinating

the resources which enabled the terminally ill patient to live in a non-institutional community setting.

2. Support systems - formal and informal

Formal support systems include services and aid provided through private and public services as well as health care agencies e.g. Doctors, Nurses, etc.

Informal support systems include services and aid provided by family and friends.

3. Family - refers to traditional and non-traditional structures (i.e. common-law relationships).

4.3 Design of the Study:

In view of the lack of research related to the primary caregiver of the terminally ill family member, and since the study sought to answer the question: How do family caregivers perceive their ability to care for terminally ill family members at home?, the descriptive exploratory approach seemed to be the most appropriate. The descriptive exploratory study focuses on the discovery of the meaning of the experience through an interview which provides a first hand account of life events.

This method of study allows the researcher to investigate the meaning of a life event for a group of

subjects who share a particular event. It also includes an elaboration of the context of the situation, as well as the retrospective happenings and prospective plans surrounding the life event (Parse, Coyne & Smith, 1985).

Leininger (1985) found that qualitative research methods reveal the broadest conceptualizations of understanding human groups and their care and health needs. "Qualitative methods give new hope to the discovery of extremely covert, subtle, and objective realities and truths about meaning and expressions of health in individuals both within health institutions and community settings" (Leininger, 1985, p.3). Tripp - Reimer (1985) agrees that qualitative research tends to be exploratory in nature and is capable of providing rich descriptive and documentary information about a topic.

The goal of qualitative research is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from the people's viewpoint or frame of reference. This includes the identification, study and analysis of subjective and objective data in order to know and understand the internal and external worlds of people. Leininger (1985) views these dimensions of knowing as essential to ascertain quality features of the informant's feelings, views, and patterns of action (or lack of action) and their interpretations or explanations.

In general, qualitative research methods focus on identifying, documenting, and knowing (by interpretation) the world views, values, meanings, beliefs, thoughts, and general characteristics of life events, situations and specific phenomena under investigation. Parse, Coyne & Smith (1985) view the qualitative approach as offering the researcher the opportunity to study the emergence of patterns in the whole configuration of Man's lived experiences. It is an approach in which the researcher is able to participate in uncovering the meaning of these experiences as they are humanly lived. The qualitative method also has the potential to generate hypotheses for further research and to enhance theory.

4.4 Selection of Participants:

The target population was identified as the primary caregivers of the terminally ill adult cancer patients who had been admitted to the Palliative Home Care Program in Saskatoon. Having been admitted to the Palliative Home Care program, all patients and families were aware of the finality of the diagnosis. Also, the fact that the patients had been admitted to the program meant that there was a similar formal support system available to all the patients and families. The philosophy along with the objectives and the admission criteria for the Palliative Home Care program are included in Appendix A.

The goals of palliative care are to help the dying patients achieve maximum freedom from physical and emotional pain; to keep them functioning at a maximal level so that they can live as fully as possible until death comes; and to meet any specific needs of the patient and members of the family that arise from the stresses associated with the final stages of illness, dying and bereavement (Ajemian & Balfour, 1982; Perrollaz & Mollica, 1981).

Another reason for choosing patients from this particular Palliative Home Care program is that in the first year of operation (1984 - 1985), more than half (56.1%) of the patients who died after being admitted to the program died at home (The Palliative Care Project Committee, 1986).

4.5 Criteria for Selection:

1. The respondent was identified by the Palliative Home Care Coordinator as the primary caregiver of an adult family member who had cared for a dying family member at home.
2. The patient had been admitted to the Saskatoon Palliative Home Care program.
3. Fifteen of the participants had cared for a terminally ill cancer patient at home until death occurred (Group I).
4. Fifteen of the respondents had cared for the terminally ill cancer patient at home during their illness prior to the

patient returning to hospital to die (Group II).

5. All participants were chosen within a time frame of 2-12 months following the death of the family member.

This time period was chosen to allow a period of time for the grieving process to take place, as well as to allow for the follow-up visits which are routinely provided through the Palliative Home Care program. The literature does indicate that the work of resolving a loss of a person takes a year or more and as the individual moves through the grieving process, a more realistic memory of events and attributes of the lost person occurs (Engel, 1964; Lindemann, 1965). The decision as to the time frame seemed appropriate based on the available literature and the routine follow-up schedule within the Home Care program.

The use of two groups provided a comparative framework as well as providing a more in depth view of the caregiver who was able to care for the terminally ill family member at home.

4.6 The Process of Selection:

All respondents meeting the above criteria were identified (54 in total). Convenience sampling was used because of the low numbers and the possibility of being unable to contact some of the possible respondents along

with the possibility of some refusals. It was decided to begin at the two month period following the death of the family member and include all eligible respondents. The time frame extended from February to November (1986) for those dying in hospital (Group II) and from March to November (1986) for those dying at home (Group I).

Once fifteen respondents in each group agreed to the interview no further contacts were made. Of eighteen who were contacted in Group I, three refused to be interviewed (83.3% accepted). Of the nineteen contacted in Group II, four refused to be interviewed (78.9% accepted). Of the fifty-four identified, many were unable to be contacted for reasons such as having moved, being on vacation or out of town visiting family. In most cases the reasons for refusal were not revealed as the potential respondent was encouraged to call the Home Care office if they did not wish to take part in the study.

4.7 Data Collection:

The data collection technique included an open - ended, semi-structured, face-to-face audio taped interview. A semi-structured interview guide (Appendix B) was used during the interview. This interview guide was based on the conceptual framework, and the literature review, as well as

interviews conducted with caregivers during a practicum assignment for the graduate class in Community Health Nursing. All interviews were tape recorded to permit accurate retention of the information obtained.

Polit & Hungler (1985) view the face-to-face interview as appropriate in obtaining data that are sensitive and personal. The interview method was chosen for the following reasons:

1. The response rate tends to be higher for face-to-face interviews.
2. Interviews are easier for many people than filling a questionnaire or responding by telephone.
3. In the practicum assignment, all respondents contacted agreed to an interview and all preferred the face-to-face interview, compared to answering questions on the telephone.
4. Face-to-face interviews offer the protection against ambiguous or confusing questions.
5. The information obtained from questionnaires tends to be somewhat more superficial than interview data.
6. Interviews permit greater control over the sample in the sense that the interviewer knows whether the person being interviewed is the intended participant.

7. Face-to-face interviews have an advantage in their ability to produce additional data through observation. The interviewer is in a position to observe or judge the respondent's level of understanding.

8. Respondents throughout the practicum assignment were very appreciative of having the opportunity to discuss this crisis in their life. One of the respondents stated, "This is the first time I have been able to talk about it since he died."

Open-ended questions allowed the subjects to respond in their own words. This method permitted the researcher to obtain information that was not preconceived. The respondents were found to be verbally expressive and cooperative which allowed for a fuller and richer perspective on the topic of interest.

Prior to data collection, approval was received from the following committees:

1. the Ethical Review Committee of the School of Nursing, University of Manitoba.
2. the Ethical Review Committee of the College of Nursing, University of Saskatchewan.
3. the Research and Development Committee of Home Care, Saskatoon District #45.

Following approval of these committees, a letter of introduction along with a letter from the Palliative Home Care Program (Appendix C) was sent to all potential subjects explaining briefly the nature of the study and indicating that they would be contacted by the researcher conducting the study. Shortly thereafter, the people were contacted by telephone to answer questions and to determine their willingness to participate in the study. If they were willing to participate, an appointment for a home visit was made at a time most convenient to them. All interviews except two took place in their own home. One respondent in Group II agreed to the interview, but preferred to come to the office as he was now living out of Saskatoon. One respondent in Group I preferred a telephone interview due to previous commitments. The length of time for the interviews ranged from one to two hours with the mean being one hour and fifteen minutes.

Two pilot interviews were completed prior to beginning the data collection. In this way the feasibility of the interview method was tested and the possibility that useful data could be collected by having the caregiver spontaneously tell his/her story was assessed. The interviews were valuable in that they provided indepth information for the researcher. In both pilot interviews, many of the guiding questions were discussed spontaneously by the respondents; therefore a checklist (Appendix D) was

developed so that only those questions which had not emerged spontaneously would be used to facilitate exploration of those general content areas. The tape recorder used with the checklist allowed the researcher to be a more empathetic listener and provided little distraction for the respondent created by note taking.

The subjects were informed at the time of the phone call that they were free to withdraw from the study either prior to the interview or any time during the interview if they so desired. The researchers name and telephone number was left with all the subjects so they could contact her if they decided to withdraw from the study or had questions to ask prior to the interview.

Prior to beginning the interview, two consent forms were signed by the respondents (Appendix E); one form was left with the respondent and the other was retained by the interviewer. Respondents were assured that they did not have to answer all the questions and could choose to stop the interview at any time.

The respondents were most willing to talk about their experience of caring for a terminally ill family member at home. There were few interruptions during the home interviews as many of the respondents had arranged for others in the household to be away at that time. Following

the interview several respondents commented on how helpful it was to talk with someone and to have the opportunity to share their experience especially if it could be of help to others.

4.8 Confidentiality:

Assurances of the confidentiality of all information shared with the researcher were made when the consent forms for participation in the study were signed. Code numbers were assigned to all checklists and all taped interviews. Only the interviewer was aware of the identifying information. Tapes were transcribed also using the code numbers and the taped interviews were erased. Personal thank you notes were then sent to all respondents assuring them that the tapes had been erased.

4.9 Data analysis:

Descriptive statistics and content analysis were used as the method for analysis. Content analysis is objective, systematic, and useful for handling qualitative descriptions of communication (Polit & Hungler, 1978). It is also a process whereby unstructured data are systematically placed into categories or units (Holing, 1986).

The interviews were transcribed in detail to identify phrases and patterns (small units of behavior) which contribute to themes. The interviews were coded first by the researcher and then 10% of the coded data was independently reviewed by two members of the research committee. Categories and properties were then discussed with few discrepancies. An interrater reliability score of approximately 80% was obtained, thereby reducing threats to internal reliability.

The Ethnograph (Seidel, Kjolseth, & Clark, 1985) computer program was used to process the qualitative data. This computer program facilitates the mechanical aspects of collecting, storing, coding, recoding, and retrieving data. The purpose of this computer program is to manage some of the mechanical tasks of qualitative data analysis while freeing the researcher to concentrate on the analytical parts of the research. The Ethnograph is able to process various types of qualitative data including transcripts (Seidel & Clark, 1984). A sample of transcripts at the coding stage is included in Appendix F.

4.10 Limitations of the study:

The small sample size and the fact that all subjects were selected from the same program limits the generalizability of the results. Because the sample was

convenience the extent to which the caregivers' views are representative of the total possible population is unknown. The fact that this was a retrospective study may have affected the respondents' ability to recall past experiences as well, their perception of the event may have been altered over time.

Another limitation relates to the willingness and the ability of the caregivers to verbalize highly personal responses, concerns and problems to an investigator whom they had only met once. The use of the tape recorder may also have caused some hesitation in sharing personal information.

Chapter 5

Presentation and Interpretation of Caregiver Interviews

5.1 Introduction

The first section of this chapter relates to the demographic data collected at the time of interview. The sample size is small, but with the breakdown between groups one can see trends developing. These trends may suggest areas for further research.

The taped interviews were transcribed and coded into various segments. These coded segments were then brought together into six categories as listed below:

- i) reactions of clients and caregivers to initial diagnosis;
- ii) characteristics of client and caregivers;
- iii) support systems both formal and informal;
- iv) decision making;
- v) caregivers reflections of their experience;
- vi) present situation.

Each of these categories will be elaborated upon throughout this chapter.

5.2 Characteristics of the population:

5.2.1 Age & sex of terminally ill family members and caregivers:

The average age for the thirty terminally ill patients was 65 with an age range of 33 to 85 years. The average age for Group I was 61 years with an age range of 33 to 85. For Group II the average age was 67.3 years with an age range from 48 to 84 years. The distribution of patients by age range is shown in Table I. The average age reported for clients on the Palliative Home Care Program for 1984 - 85 was 65.1 years (The Palliative Home Care Pilot Project Evaluation, 1986).

The average age for the thirty caregivers was 59 with an age range of 31 to 77 years. The average age for Group I was 54 years with a range of 31 to 77 years. For Group II the average age was 65 with a range from 49 to 73 years. The distribution of caregivers by age can be seen in Table I.

There were more female patients as well as more female caregivers within the group (Table I). The ratio of female to male caregivers was the same for both groups, nine females to six males.

Table 1

Age, gender, relation of caregiver to client and income:

	Group I %		Group II %		Total %	
	N=15		N=15		N=30	
<u>1. Age of client</u>						
20-39 yrs.	2	13.2%	0	0.0%	2	6.7%
40-59 yrs.	4	26.7%	4	26.7%	8	26.7%
60-79 yrs.	8	53.3%	8	53.3%	16	53.3%
80+	1	6.8%	3	20.0%	4	13.3%
<u>2. Age of caregiver</u>						
20-39 yrs.	3	20.0%	0	0.0%	3	10%
40-59yrs.	7	46.7%	2	13.2%	9	30%
60-79yrs.	5	33.3%	13	86.8%	18	60%
<u>3. Gender of client</u>						
Female	10	66.6%	9	60%	19	63%
Male	5	33.3%	6	40%	11	37%
<u>4. Gender of caregiver</u>						
Female	9	60%	9	60%	18	60%
Male	6	40%	6	40%	12	40%
<u>5. Relation of caregiver to client</u>						
Husband	5	33.3%	6	40%	11	36.6%
Wife	5	33.3%	6	40%	11	36.6%
*Other	5	33.3%	3	20%	8	26.7%
<u>6. Income</u>						
Adequate	14	93.3%	14	93.3%	28	93.3%
Inadequate	1	6.7%	1	6.7%	2	6.7%

*Includes common-law, friend, cousin, daughter-in-law, sister, daughter & neighbor.

5.2.2 Relation of caregiver to client

As shown in Table I the number of husbands and wives in each group was equal with an average of 36.6% of each in the total group. Thus leaving 8 out of 30 or 26.7% of the total group to come under other which included common-law (1), friend (1), cousin (1), daughter-in-law (2), sister (1), daughter (1) and neighbor (1). The slight increase in husband and wife relationships in Group II is concurrent with the slight increase in age of the Group II clients as well as the Group II caregivers.

5.2.3. Income

Income did not seem to be a factor in determining whether the clients remained at home or returned to hospital as there was only one caregiver in each group who reported their income was inadequate. All the rest (28) reported their income as being adequate (Table I).

5.2.4 Education of client & caregiver

Twice as many clients with an education beyond Grade XII died at home as compared to the group that returned to hospital to die. Similarly, it was found that twice as many caregivers in Group I had an education beyond Grade XII as compared to Group II. The larger difference in caregiver education can be seen in the area of less than Grade XII where there was 73.3% or 11 out of 15 in Group II and only 4 out of 15 or 26.7% in Group I (Table 2). This

factor may be explained because of the older average age of Group II but may well be a factor for further exploration.

Table 2 Education of clients and caregivers.

	Group I %		Group II %		Total %	
	N=15		N=15		N=30	
<u>Education of client</u>						
Below Grade XII	4	26.7%	7	46.6%	11	36.6%
Grade XII	3	20.0%	7	26.7%	7	23.4%
Beyond Grade XII	8	53.3%	4	26.7%	12	40.0%
<u>Education of caregiver</u>						
Below Grade XII	4	26.7%	11	73.3%	15	50%
Grade XII	5	33.3%	1	6.7%	6	20%
Beyond Grade XII	6	40.0%	3	20.0%	9	30%

5.2.5 Religious & Cultural Background

The majority of respondents (66.6%) were white Anglo-Saxon which is representative of the population in Saskatchewan, and in particular Saskatoon, since 45% of the population in Saskatchewan and 47% of the population in Saskatoon are white Anglo-Saxon (Statistics Canada, 1981).

Eighty-three percent of the total population reported having a religious affiliation (Table 3), whereas 16.6% said religion really did not play a part in their life. In Group I, 11 out of 15 (73.3%) reported the minister had visited at home during the time they cared for their terminally ill family member at home. Three of those who reported the minister had not visited at home also reported not having a religious affiliation. Therefore, of those in Group I who

reported a religious affiliation only one did not receive a visit by the minister at home. In Group II, 10 out of 15 (66.6%) reported the minister visited at home. Of the five not visited two reported being non-denominational. Religion as a support mechanism will be addressed further in section 5.5.5.

5.2.6 Years of Marriage & Living Arrangements

Years of marriage did not seem to be a factor in whether the family member remained at home to die or returned to hospital. In relation to living arrangements ten (66.7%) either lived with spouse or with spouse and children which was similar to the eleven (73.3%) in Group II. It was also noted that two in Group I lived alone whereas no one in Group II lived alone.

5.2.7 Occupation

In Group II (Table 3), 14 out of 15 (93.3%) of the caregivers were either retired or were not working outside the home. In Group I, 8 out of 15 (53.3%) were either retired or not working outside the home, the other seven were working in their own independent business or were employed on a part or full time basis. The fact that 86.8% of the caregivers in Group II were over 60 years of age as compared to 33.3% in Group I may be one explanation for the difference in numbers of caregivers working outside the home.

Table 3 Religion, culture, years of marriage, occupation and living arrangements:

	Group I %		Group II %		Total %	
	N=15		N=15		N=30	
<u>Religion</u>						
United	4	26.7%	8	53.3%	12	40.0%
Catholic	4	26.7%	3	20.0%	7	23.4%
Non- denominational	3	20.0%	2	13.3%	5	16.6%
*Other	4	26.7%	2	13.3%	6	20.0%
<u>Culture</u>						
White Anglo-Saxon	12	80%	8	53.3%	20	66.6%
**Other	3	20%	7	46.7%	10	33.3%
<u>Years Married to client</u>						
0-9 yrs.	1	6.7%	2	13.3%	3	10.0%
10-19 yrs.	2	13.3%	0	0.0%	2	6.7%
20-29 yrs.	1	6.7%	2	13.3%	3	10.0%
30-39 yrs.	3	20.0%	2	13.3%	5	16.7%
40+ yrs.	3	20.0%	6	40.0%	9	30.0%
not appropriate	5	33.3%	3	20.0%	8	26.7%
<u>Occupation</u>						
Retired or not working outside the home	8	53.3%	14	93.3%	22	73.3%
***Other	7	46.7%	1	6.7%	8	26.7%
<u>Living Arrangements</u>						
With Spouse	7	46.7%	10	66.7%	17	56.7%
With spouse & children	3	20.0%	1	6.7%	4	13.3%
With adult children	1	6.7%	1	6.7%	2	6.7%
With other relative or friend	2	13.3%	2	13.3%	4	13.3%
Alone	2	13.3%	0	0%	2	6.7%

*Includes Alliance, Baptist, Lutheran, Mennonite, Salvation Army.

**Includes Czechoslovakian, German, Jewish, Norweigan, Swedish & Ukranian.

***Includes secretary, store clerk, writer, independent business & nursing.

5.2.8 Caregiver's Health

In Group I only one caregiver reported having more than one health problem whereas in Group II, 8 out of 15 (53.3%) reported having more than one health problem. The

major health problems referred to by the respondents were back problems and nerve problems followed by arthritis and heart problems. In Group I six or 40% reported their health to be good (no health problems) whereas only two (13.3%) in Group II reported their health as being good. In relation to caregiver's health since the death of the family member, thirteen (86.7%) in Group I reported their health had remained the same, one reported it was better and one reported it was worse. In Group II, eleven (73.3%) reported their health to be the same and four (26.7%) reported it as being better. This area will be expanded upon in 5.4.2.

5.2.9. Previous Health Care Experience

When asked whether they had had any previous health care experience - five (33.3%) in Group I answered yes and one (6.7%) in Group II answered yes. Most had never had any experience in caring for someone who was very ill. Of the caregivers who reported having previous health care experience two were nurses (one from each group), one was a CNA, one had worked in a nursing home, one had taken the St. John's First Aide Program and one had been a lab technician.

5.2.10 Primary diagnosis and Length of Illness

All respondents had cared for a terminally ill family member who had been diagnosed with cancer. The type of cancer was varied in both groups (Table 4). This age

group and the fact the primary diagnosis was of a malignant disease is similar to most hospice programs. In the Saskatoon Palliative Home Care Program (1984-85), 95.4% of the clients had a primary diagnosis of a malignant disease (The Palliative Home Care Pilot Project Evaluation, 1986).

The length of illness was the time since diagnosis of a malignant disease. The length of illness was similar for both groups (Table 4). The time on the Palliative Home Care Program varied depending on the particular situation. These situations will be elaborated upon in the following sections.

Table 4 Primary Diagnoses and Length of Illness:

	Group I %		Group II %		Total %	
	N=15		N=15		N=30	
<u>Diagnosis</u>						
Breast	3	20.0%	6	40.0%	9	30.0%
Bowel	3	20.0%	3	20.0%	6	20.0%
Pancreas	3	20.0%	1	6.7%	4	13.3%
Lung	3	20.0%	3	20.0%	6	20.0%
Cervix	1	6.7%	1	6.7%	2	6.7%
*Other	2	13.3%	1	6.7%	2	6.7%
<u>Length of Illness</u>						
Less than 6 mos.	4	26.7%	4	26.7%	8	26.7%
6 mos. to 1 yr.	5	33.3%	3	20.0%	8	26.7%
Over 1 yr.	6	40.0%	8	53.3%	14	46.6%

* Includes sinus, stomach & multiple myeloma

5.2.11 Summary

The three factors identified from the demographic data which may suggest reasons for hospital admission compared to remaining at home are: age of patient and caregiver, education of patient and caregiver, and health of the caregiver. The factor related to age may explain the other two factors but a much larger sample is required to determine if there is a relationship between these factors.

The fact that 73.2% of the caregivers are spouses may suggest that the age of the patient and caregiver will be fairly similar, as the average age of the patients increase so will the average age of the caregivers. Since a higher level of education was found in the group who remained at home to die, this may have implications for the future as the overall population becomes better educated. Another factor which became apparent was that Group II caregivers reported having more health problems than the caregivers in Group I. Forty percent of the caregivers in Group I reported their health as good whereas, only 13.3% of Group II reported their health as good.

Because of the small sample size it is important not to generalize the results of the study but to use the results as a basis for testing and generating hypothesis related to these variables.

5.3 Reactions of clients and caregivers to initial diagnosis

5.3.1 Introduction

This section has been written in more detail to introduce the reader to many of the families and to demonstrate some of the concerns and problems which became apparent to the researcher. Caregiver responses will be reported by group so that any important differences between groups may be more apparent.

5.3.2 Reported reactions and concerns of Group I

Many of the caregivers expressed frustration with the initial diagnosis, with physicians telling them what the information meant and with the initiation of treatment.

In September, the doctor at the cancer clinic told her it was affecting her liver, but said to her, "We will see that you get out golfing yet" which we knew very well afterwards that she shouldn't have told her because the doctor knew better than that. When we got home the wife looked in the doctor book and it said that once it affects the liver there is not much the doctors can do for you.

The physician she had at the time was one neither of us respected but you don't know what to do and are not sure you want to change. When M. started going to the doctor she kept telling her colitis, colitis and made her feel guilty for feeling stress. This doctor was finally going on a six month leave, that was the best thing that could have happened.

I think if we had had a damn good doctor he would have got to this sooner - that's what I think. She doctored from June 1984 and only found out on December 24/84 that she had cancer - I

think and she thinks that it could have been caught sooner. We waited six weeks from December 24. There were no beds available in the hospital. The cancer was growing inside of her all this time. The waiting was the worst thing you could do.

She went to her doctor. He said her cervix was eroded. He never did a pap test but did cauterize. It didn't seem to have any effect. As time progressed she went through more tests and was confirmed cancer after six months of when she started going to the doctor.

The mistake she made was not getting a second opinion. She had dealt with this doctor for a few years and was confident in him.

I hate to criticize the medical field you know. He had been doctoring close to a year and was being treated for allergies when really what he had was cancer of the sinus and it wasn't until one eye started to protrude and I noticed it that I insisted that he go back. He went into the hospital and had a biopsy and they said there was nothing they could do.

That was the most difficult time for me because I felt helpless. I always believed that if you thought positive you could accomplish anything and here they were telling me there was nothing I could do and that was kind of hard.

They didn't tell him they told me and you know how doctors don't want to tell the whole truth and they sort of step around it - wow, did they lay it on me - we never expected it wouldn't be treatable. This was over the phone and K. was in the hospital and they hadn't told him. I was going up to see him every day and pretending I hadn't heard anything.

It was the day before he was discharged and finally he said the doctor had told him it was cancer and he didn't know if it was operable. They approached him with a more positive outlook that they were going to try and do something. They told me they couldn't do a thing. That was difficult too because he came home wondering when they were going to call him for treatment and what they were going to do and me they were saying there was nothing they could do.

Some clients never did accept the diagnosis of cancer while others were more accepting:

The doctor phoned her and told her. She was on her own that day. She phoned me and told me. She was upset so I went over. She always talked about this thing she had but didn't really accept it was cancer.

He found an adhesion by the bowel and didn't want to send her for more tests once he found it was cancer. He said if she wanted to go and see a specialist it was fine, she could go, but she decided not to. You know, she trusted her doctor so she decided not to.

He was admitted for prostate surgery and pre-surgery tests showed up the tumor in his lung. At that time it was to the stage they couldn't do surgery so was booked for radiation treatments which he took very well. That was all they were able to do for him. They knew right from the very beginning that they couldn't do anything.

He stood up to it well. I don't imagine there were many people who accepted it the way he did. He had a bad day when they first told him but other than that he was just super. He supported me more than I supported him.

It was something we were aware of and we lived with it. We were told and had no trouble talking about it. He often used to say, "If I just had a couple more years."

5.3.3 Reported reactions and concerns of Group II

The reactions expressed by the caregivers in Group II were very similar to the frustrations and stress felt by Group I.

He had made an appointment to see the doctor so he went and had x-rays and everything and they found out he had a hiatus hernia. He was really getting weak and wasn't eating so we thought there had to be something else. We went back to the doctor and told him this had been going on long enough. We wanted to know what was wrong. So he referred him

to a specialist. After several tests the doctor called us to the hospital and told us it was cancer but said there was nothing to worry about. He suggested surgery and treatment so we had our hopes built up. They said they would get him in for surgery next week. This was the first part of May.

We waited. We got a letter from the hospital and he was to be admitted to hospital the end of May. He was getting pretty weak by this time and couldn't sit much. He wasn't eating. On May 14 he got up and could hardly walk. So we got in touch with the doctor and told him we couldn't wait until the end of May because he was getting so weak and I couldn't handle him - lifting him up and helping him. He was trying so hard to do it on his own but he couldn't. When I phoned the doctor on the fourteenth I was so upset because he was so sick. I said, "He can't stay home right now. There is something drastically wrong and he is getting sicker" and I said, "Either you put him in now, today, or I am bringing him in through emergency today because he is coming in today and that is all there is to it." He just couldn't hardly walk to the bathroom.

The doctor called me back and said the hospital would try to get him in this afternoon. If not, he said it would be tomorrow. But I said, "I'm bringing him in this afternoon because he is just too sick." By 2:15 the hospital had called me and I had him in hospital within half an hour. They gave him a cat scan.

Now we knew he had cancer but had been told it was a little tumor that we wouldn't have to worry about. I talked with the doctor after that and he said, "It doesn't look good at all." So after the cat scan the doctor called me to go to the hospital and the doctor told us both that it was terminal. I think he explained everything to us but I can't remember a lot of what he said. He said there was no way they could operate on him to do any good.

He got a pain in his knee cap. It was steady pain. He went to see the doctor and the doctor said it was arthritis. He gave him an appointment with a specialist but he couldn't get in until September - June to September was quite a few months. In June he gave him pain killers but he couldn't get rid of the pain. In September, they gave him x-rays and found the cancer was eating him all over the place. See what I mean - all the time they wasted from the twelfth of June until the

twenty-seventh of September. The doctor asked me to come to the office and he said, "I think your husband is full of cancer." My whole body was just weak. I said to the doctor, "Why couldn't you have seen him sooner. I told you he had pain and it wouldn't go away." Nobody told him anything he said.

They put pins in his leg. He had treatments but the treatments killed him I think. They tired him out. At Christmas time he got into the wheelchair. After Christmas, he suddenly went down more. After January, he couldn't even get out of bed. He just had no strength.

While we were on holidays she had a slight blackout. The doctor there suggested she have a good check-up when she got home which she did and on July 25th the doctor told her she had cancer on the lung and seven months later she was dead. I am angry and still am for that matter that it took seven weeks before she could get a hospital bed. That to me is inexcusable, especially when they advertize that cancer can be beaten if you catch it in time. There wasn't much of a catching there. Why did they wait so long?

When she did get into hospital they took a biopsy of the lymph gland and it had already spread, therefore there was no need for an operation and she was sent home.

As with Group I, some of the experiences associated with the time of diagnosis were less traumatic for both patient and caregiver but nevertheless revealed a very stressful time for both and how they reacted to this stressful situation varied with each individual.

In February he had surgery and they said it was malignant and was a large tumor in the pancreas. They had told him at that time it was terminal.

It was a shock at first when they gave him the diagnosis but he really had a powerful mind and he was very strong and whatever the outcome would be he was one that could face up to it.

After we found out the diagnosis we came home and we both just broke down and cried. There was only

twice that we cried together, but we never talked about it.

When she was at the cancer clinic the doctor showed me the x-rays of her lungs. You could see the spots. My wife said, "I'm sure glad its not cancer. How can it be, I don't smoke. I don't do anything I shouldn't." The doctor said, "I'm afraid that is exactly what it is."

When she told me she had cancer I couldn't answer. She asked if I heard her. I said, "Yes, I heard you."

She never complained. She accepted it for what it was and was never angry. It sure wasn't because she was tired of living.

5.3.4 Summary

Many of the caregivers in both groups expressed a great deal of frustration and anxiety related to the time of diagnosis. At times there was frustration expressed in relation to the delay in diagnosis, the delay in getting into hospital for treatment and the manner in which many of them had been told about the illness. Because of delays in diagnosis and the lack of available treatment when it was needed, there was a great deal of resentment that still lingered as expressed in the comments above.

The caregivers seemed to remember very clearly many of the activities which took place around the time they found out that their family member had cancer. This period of time was very traumatic in their lives and for many it still brought tears to their eyes as they reminisced. Many of their feelings were captured in their dialogue during the

interview. It was found that all caregivers who had agreed to the interview were very willing to share their experiences and to relive this period of time in their lives.

There also seemed to be a general feeling expressed by the caregivers that following the initial shock of the diagnosis they were able to reorganize their thoughts and look for ways to make the best of the time that was left to them.

5.4 Characteristics of clients and caregivers

5.4.1 Characteristics of the client

This section describes the physical and mental characteristics of the client as described by the caregivers in Group I and Group II.

Group I

Many of the caregivers in Group I indicated there was little exchange of conversation in the last few days of life but there was an understanding and the knowledge of what they had agreed to prior to reaching this stage of the illness.

The last week she was semi-comatose. Kind of in a dream state but then would come out of it and be very lucid and knew what was going on. You could see the deterioration day by day. The last five days she didn't say a lot. Probably the last time she recognized me was three days before she died.

It was hard to communicate with K. because he was deaf and blind at the end.

The last couple of weeks she just really lost the ability to communicate. She couldn't really talk to us and explain what she wanted so it was hard.

You know, there were some days for two or three days he would be quite confused, then he would have a little nap and when he woke up he would know everything that was going on with the news - everything.

She was able to get up and have breakfast until just a week before she died. But then just exactly a week before she died her arms seemed to go kind of rigid and she couldn't feed herself, so it was only the last week we were feeding her. The last couple of days she went into a coma.

Many caregivers described various physical problems which were experienced by their family member during those last few days of life:

Up until the last few days my wife was able to get up and walk around. Not more than three-four days that she was in bed all day. She just slowly deteriorated. The last two days she just mostly whispered. She could communicate with us right up until the last.

The last months he was completely bedridden and the nurses came more often (3 times a week). Towards the end he was having so much pain that it was hard to turn over. He was able to help turn himself up until one-half hour before he died and

we were able to manage okay. I didn't think it was a chore.

Incontinence was a problem for her but we managed. The last week she started to have seizures. She became very dehydrated before she died.

Just the last two weeks he was in bed all of the time.

There wasn't that much extra work other than the last ten days or two weeks where he was really ill. Prior to that I don't feel I was put upon.

Her biggest problem was the nausea. She was extremely nauseated and it was extremely hard to keep enough liquid in her. She was very aware, up until the last week before she passed away. She really didn't want much medication and was very aware what it all was for. She even found the Gravol made her drowsy and she didn't want that. She was very much in control and that is one thing about being at home is that you can call the shots.

He looked just like a corpse. He was so weak he couldn't even keep his mouth shut and yet he was trying to walk. The weight just came off. He lost pounds in a matter of days. He started out at 185 pounds 6'1". At the end he weighed just over 100 pounds. At times he was quite confused. Other days he was really alert.

Many caregivers reported how co-operative the patients in Group I were during the time they cared for them at home.

She was so accepting of death that her attitude made it so much easier to care for her at home.

He never complained. He was always so grateful.

It was hard for her to admit that she was going to die. Near the end she was beginning to be very nervous about being on her own. At night time especially. She was always so glad to see me when I came in the morning. I had a key to her house.

Right up until the end he was co-operative.

He never ever once complained. I wish he would have.

Group II

The attitudes of the terminally ill relatives were discussed more than the physical characteristics by the caregivers in Group II.

Statements relating to physical characteristics:

He was getting so weak and I was so afraid he would fall.

It got so I couldn't lift him. That is another reason I needed so much help because my back was so bad. He needed a lot of help just to get to the bathroom.

Once we got the pain under control it wasn't too bad. She wouldn't eat anything or very little. The feeding bit was a real problem. Once the pain was under control she was able to walk around the house a bit using the canes.

Statements relating to attitudes:

Some of the psychological characteristics mentioned of patients in Group II were - perfectionist, independent,

stubborn, self-determined as well as other characteristics such as having a positive attitude, cooperativeness, not a complainer, loneliness, acceptance and a sense of humor.

She didn't want help. She didn't want to bother anyone - that's the way she was. She wanted to make it as easy as possible but there were times that I had to help her.

She was a perfectionist and God help anyone who has to live with one of those. Secondly, she was a very demanding person and also very self-centered. She didn't give a damn for anybody but herself and her own wishes even to the exclusion of her own family.

She was one in a million. She just amazed everybody with her attitude and how she kept going. I think an awful lot of it really is the attitude of the patient. Their willingness to try and get along with people.

I found out too with her she was more lonely than anything else. For quite a while she was still in a wheelchair or could use the walker then she would come out and we could eat together. Then later on when she was bedridden she wanted me to come and eat in her room, so I did.

He was a very stubborn man. He had a mind of his own.

He told his sons one day, "Death is nothing to be afraid of." He spoke quite freely.

He was the kind of person who never complained about anything or anybody. Even in the hospital not once did he complain.

By the first of October he no longer wished people to come to visit. Immediate family it was good. He loved music so we played music in his room a lot and he liked that.

It bothered her that I took care of her. She was always very self-determined and that anybody should have to do this for her especially her own immediate family - she just couldn't stand it.

If I would leave for an hour and if I was five minutes late she would be so upset.

She was a good help. She was a good patient. We were able to talk about it openly. I used to say, "If I have cancer don't tell me about it, but I have changed my mind completely. She had such peace. She was calm, collected, she was at ease all the time. We could talk about it just as though she had a sore toe. She was never angry or upset - why should I have it yes - but never angry. She knew this was going to be the end of it and it was just a matter of time.

She had a good sense of humor and always tried to make the most of everything.

She really wasn't afraid to die but would talk so positively. She really thought she was going to get better. She was a very good person - very generous. You felt you could say anything to her and she wouldn't judge you. That kind of a person makes them easy to care for.

Many of the caregivers reported that many of the clients wanted to remain at home if at all possible and often requested to return home after being admitted to hospital.

He was wishing he could come home he was just getting bored there.

She wanted to remain at home as long as possible. She only agreed to going to hospital for treatment.

When he could, he wanted to be at home. When he was in hospital for a few days then he would want to come home.

He was only in hospital a few days and he was asking to come home. That was hard because we knew he wasn't going to be able to come home again.

5.4.2 Characteristics of the caregivers:

Group I

It became apparent that the caregivers in Group I were feeling considerable physical and mental stress, yet they were able to continue providing care for their terminally ill family member in order for that person to remain at home until death. Many felt they seemed to receive the additional strength that was needed in order to carry on. Some of the additional supports that the caregivers found helpful were family and friends, their faith, their physician, the help they received from home care as well as just living one day at a time.

I don't know how I did it. He was so strong. Occasionally I didn't cope but for the most part you just had to cope because you couldn't take him down because he was fighting so much. If I really got down I would go to one of my friends and do the whole thing in one evening and then carry on again.

I felt I was helpless at times because he was suffering and I couldn't do anything to help him.

The doctor was very concerned it would get me down. The minister made me promise to get out for a couple of hours a day and have someone else take over. I was able to do that because there were people who would come. I had never experienced anything like this before.

Stress was the hardest part. She didn't want me to go away at all.

In a situation like that you say this is the way it is. There is no point in breaking down. It wasn't going to help the patient.

I work better under stress. It was surprising, I wasn't that tired.

At the time he was so sick I wondered how I could go on but you get some inner strength from somewhere and you are able to carry on.

It never bothered me that he was going to die at home.

The thing I found the hardest was he didn't want me out of his sight. He was just afraid of me going away. If I was going downtown I just couldn't tell him the night before because he got so upset. I found this was a strain because I felt guilty leaving him and yet I had to.

Everyone told me she was dying but I didn't want to hear it.

I just took it like an alcoholic - one day at a time because I never knew what the next day would bring.

Towards the last her sister really broke down. She just couldn't see why. I don't know if it was our faith that brought us through. I think it is - like - we were prepared and if this was the way it was supposed to be.

It didn't bother me to give the care. Bedpans etc. didn't really bother me.

I was glad to know about home care because I'm a squeamish person.

I don't think a lot of people can do it. When she had her seizures I had some first aide so I knew something I could do.

I was giving feeding and medication by tube as well as giving insulin four times a day. The home care nurse taught me how to give the insulin. It worked really well. I was so scared of it.

I wasn't able to rest. The home care wanted to send someone and my sister offered to help but I wanted to do it myself.

Looking after her didn't bother anyone. It was stressful especially with us being responsible but really we did very well. It was difficult with our children being so young.

I pretty well knew what to do when she passed away because I had worked for VON and with Nightingale Nurses. I think my past experience really helped me get through it.

Group II

Several caregivers in Group II expressed anxiety about their family member dying at home.

I was worried about her passing away in my house. The nurse had warned me about it and had talked to me about it and had told me exactly what to do if anything happened but when I personally felt it was getting towards the end I got nervous about it so I thought, "Well, whether the Nightingale Nurse is here or not I would sooner have her die in hospital." I am not sure why that made me nervous. I suppose it made me nervous because I didn't know at that time just how people pass away - what happens. I think that's likely what made me

nervous. Now having been with her right up until the end at the hospital, I don't think it would bother me quite so much another time.

I felt if I had seen her die in this room I could never stay here. I had never experienced anything like this before.

The idea of him passing away at home really bothered me. I don't know whether I could have handled it.

I think it would have bothered me very much if she had died at home.

I wouldn't have wanted him to die here. If he had of I never would have stayed here. I would have never made it. It was really better that he died in hospital.

Caregivers in Group II also described the emotional and physical stress they were under and how they were able to cope.

I had my doubts when I brought him home. I was so scared to have him home because I had never had anybody that sick so I didn't know how I could cope with it, but God, I wish I had brought him home earlier.

It's amazing the strength you are given when you need it You are given the strength to cope. My physical health being what it was there wasn't one day from the beginning of his illness that I wasn't able to go from morning until night. Through the whole thing it was as though I had never been sick. I just know I was given extra strength to cope with everything.

I was with my brother when he died and I was just so glad I was. I think this experience with my brother gave me some of the strength to go through

all of this again. I really think that experience helped me to know what to expect.

At that time I had regained a fair amount of strength except the stress factor was getting very bad. In fact I had had one attack while I was up visiting at the hospital. They took me to emergency and it was an acute anxiety attack. I knew I had had the biscuit.

As far as I am concerned there was an obligation and no matter what the circumstances are you have to live with it. I'm a peculiar chap. Obligations mean a lot to me. No matter what my feelings were I had obligations. It was my responsibility to do what ever I could to keep her as comfortable as possible and that was it.

I never had any help. I did it all myself. I just wish we had had home care earlier. The home care co-ordinator was going to send in somebody twice a week so we could get out because she could see that we needed to get out. At the last we couldn't go out. She used to say we should go out but we just couldn't. If something had happened while we were gone we just never would have forgiven ourselves.

I was tired and I worried. You were always afraid of something happening to them. The minute she was up I'd be up because I was always afraid of her falling and breaking a bone or something.

This is the first time I had ever cared for anyone like this and I didn't know if I was going to be able to do it or not but I guess the Lord gives you strength to do it, you know.

It's a mental strain as well as a physical strain.

We would have had to have a hospital bed and all that other stuff and I just couldn't do it. We had no room for a hospital bed and he wouldn't have got all those pills and this, that and the other thing if he was home. I just couldn't have done it.

I coped very well until towards the end when I began to worry about how she was sleeping and that.

For a while I felt hemmed in - that's why I think if I had had the nurse sooner.

It really bothered me because he was unable to talk about dying - how he felt - never once did he talk about it. I wanted so badly to know what he was thinking.

I didn't really want to go out I just wanted to be here.

She had pills for the pain every four hours. You had to get up twice a night. She was also having a problem with constipation because of the medication. It was no picnic.

It really changes your lifestyle having someone around like that.

I had hip problems at the same time and it was hard for me to walk. My hip gave out on me at that time. I had that operated on this fall and it is much better (6 months after wife's death). I should have had it done earlier but I didn't want to bother because she was not well.

It was an accident four years ago and I have been on disability since that time. I had the whip lash. I have been going to doctors ever since with this pain in my back and it has now gone into my shoulder. I get such terrible headaches. So I had this all to cope with during the time he was ill, but actually I never thought too much of myself at that time.

I have a nerve problem and back problems. I have also had many surgeries. I have this nervous stomach and I have to watch what I eat.

They started me on the tri-hospital heart group at the field house. First there was the lecture series which was from 11-1. When someone was in the house I was able to go to that which apart from giving me support there it also gave me a break out of the house which I needed very badly. Then I started on their health program so that and the home care were my salvation because then I was able to get my strength back and do a few extra things. A little more cooking, the shopping, etc..

5.4.3 Summary

The caregivers were able to accept and work through their problems related to communication knowing they were fulfilling the wishes of the patient. The caregivers also shared some of the physical and mental problems which the client experienced. These problems ranged from being deaf and blind, to being in a comatose state, incontinence, nausea and vomiting, seizures, dehydration and confusion. Even with coping with all of these problems they were able to provide care for their terminally ill family member until death. Many caregivers reported that the client themselves, had coped very well and had remained cooperative right until the end.

In Group II there was more mention of the psychological characteristics rather than the physical characteristics of the client. Part of the reason for this may be the fact that when the patient became physically difficult to manage he/she returned to hospital. The time

spent in hospital prior to death ranged from nine hours to four months, the mode being three weeks.

The caregivers in Group II also mentioned how many of the clients wanted to remain at home. Ten out of fifteen (66.7%) indicated that the clients would have preferred to remain at home if at all possible. The reasons why the client returned to hospital will be discussed in the section on decision making (5.6.2).

In Group II several caregivers expressed anxiety about their family member dying at home. Seven of the caregivers (46.7%) indicated specifically that they did not want their family member to die at home. This group also identified many health problems that were reported in the section on the caregiver's health (5.2.8). In Group I, three (20%) reported having a nerve problem whereas in Group II - eight (53.3%) reported having a nerve problem. This may help to explain many of the anxieties expressed in Group II along with the fact that since the death of their family member four of the caregivers reported their health had improved.

Some of the caregivers in Group II agreed with those in Group I that they were given strength when they needed it, but there were others in Group II who felt they just could not go on any longer.

5.5 Support Systems

There were many support systems identified by the caregivers as important factors in the length of time and in how well they were able to manage caring for their terminally ill family member at home. These support systems are presented alphabetically, as the importance of each support system varies with the situation and the resources which were available during that particular period of time.

5.5.1 Family

Group I

The majority of caregivers in Group I reported on the value of family supports. Family helped out in many different ways at many different times. They helped with the physical care as well as provided moral support. One family member who was also a physician was able to administer the IV therapy which was given at home. Other family members took a leave of absence from work just so they could be there.

My wife's sister lives just down the street. For the last couple of weeks she was here everyday. This was a real help especially when I was at work, otherwise I would have had to stay home.

My daughter was also living at home at the time - she was very helpful. Our oldest daughter came home for the last couple of days and was able to spend all her time with her mother. Our two daughters sat with her all night. She passed away in the morning. All the family were there. It was very peaceful not even a gasp for air or anything.

I was between jobs which allowed me to spend a lot of time with my mother. She stayed with us for the last six weeks. Our older sister who lives out of the city was able to help out as well. She works one week and gets a week off so she would come on her days off. My other sister would take days off work as well when we needed her. We took turns at night so we would get a good nights sleep every other night. She seemed to be more comfortable when we were with her at night.

All the family had been here on the weekend - she passed away the next day. It was quite peaceful. Family were the main support.

When I needed to go out our daughters would come and stay. I was by myself until the last night when I called my brother and he stayed until 7A.M.. Our oldest daughter was here when he passed away. I never felt alone. My older daughter was here a lot.

We had four daughters here in Saskatoon. One daughter was a doctor therefore we were able to give the I.V. therapy at home. Most of October and November family were here. Our daughter who is a Psychiatric nurse took a leave of absence to be here. All the family were here the day she passed away. Family was very supportive - they couldn't have been more helpful.

Family supports are very important. Her mother and father came and stayed for one month before she died. I think the fact that her folks were here, that helped a lot. Her parents were very supportive throughout the entire illness. If her parents had not come and stayed for the last month I think I would have found it pretty well impossible to cope.

Our daughter is a nurse and my sister is a nurse. I really wasn't doing this on my own. I had a lot of help and support. There was really nothing they could do but the fact they were here was a help. There wasn't a great deal anyone could do. Both my sisters, our daughter and our doctor were here when he died. Family supports make all the difference in the world.

Our two daughters here in Saskatoon were really good. The last week our daughter from P.A. came and stayed the week. One of our other daughters would come and stay the night. That was only the last few days. The day she died the nurse bathed her, then one of our daughters was here with me when she died.

Both boys were living at home during their mother's illness and were quite a help. They used to help with the lifting. My daughter came for two or three weeks and that helped. The boys were here when she passed away.

We had to have extra people working at that time so I could stay home with him. If I did have to go out my sister would come over and stay. My sister - I don't know what I would have done without her. She was my backbone. The last three weeks that he was ill she moved right in with me.

I'd sit by the hour and rub his back. When my arms would play out my sister would take over until finally he would fall asleep. This seemed to help the pain more than anything. My sister couldn't do any lifting or anything but moral support was my big thing. If my sister hadn't been able to stay I would have needed someone to come and stay just for my own sanity.

My sons and daughter spent a lot of time here but they didn't stay overnight. They spent time pretty well every day with him. Our daughter here in town was really close to her Dad and just wouldn't accept he was going.

The family is quite large (5) but they all live away from Saskatoon except for my husband. The other family members all agreed to come and spend a week at a time with her. She also had a sister in Calgary that said she would come. When we brought her back to her suite there was someone with her all the time. Her daughter was here for at least the last month. The days there wasn't a family member here the Palliative Home Care would take the sixteen hours, then my husband or I would take turns going over and sleeping there. So it worked out well but it was very stressful. Three or four members of the family were there when she passed away. The last two weeks we just really wondered what kept her going.

Her sister came every night and helped her get ready for bed. Her sister provided a lot of help. Our daughter, who is a nurse, came and stayed with us for the last week. My daughter and her husband and my second son were with her when she died. I think it was having the support of other members of the family that helped me cope. Her sister was right there all the time. There is no way I could have managed without all the family support and help.

Group II

Family was found to be supportive for the caregivers in Group II but often were not as available as the family supports in Group I.

When she came to live with us my husband was a big help because he loves to cook and if she wanted certain things he'd make it. My sister helped out quite a bit. When V. was still well enough she used to go and stay with her a week at a time. That gave me a break also. I also had a sister from the east and the west come to spend time with her.

Family never really came and stayed for any long period of time. My daughter came when she could. My sister was a big help. She came and helped when she could.

His son would come in a couple of hours a day when he could. This did help. Otherwise, there was no family to come and help.

She had a daughter and a son out of town who used to come and just visit once in a while. She also had a mother (83 yrs. old) who was more of a detriment than a help so she didn't come too often. My daughter and son-in-law did a lot of the shopping and things.

My sister came and stayed an odd night so I could get some sleep. My kids were here whenever I needed them. They were over every day to spend time with their Dad.

My daughter from Vancouver came and stayed for the month of June. Then my daughter who was the Psychiatric Nurse stayed for the month of July. That was a real help for June and July. He had to have enemas and she was able to give them to him. She was only able to come three days a week in August. It was really difficult for me to manage by myself. Once she wasn't able to be here all the time then he started spending more time in hospital. I relied a lot on my daughter for June and July.

My daughter is a nurse. She took a lot of time off and was here a lot of the time. She was a big help. She only stayed with me a few days. Usually she would just come and go.

Friends and family did not help out very much.

My daughter used to come and stay once in a while.

They never stayed with us much while I was caring for her at home but they did visit quite often.

My son and daughter were home a couple of times but never stayed that long. My son was here just before she passed away.

The family didn't really help much.

I don't think I could have done it if our family hadn't been so good with her too. My husband was very supportive. I wasn't there all the time near the end when she was in hospital but her sister stayed with her most of the time.

5.5.2 Friends and Neighbors:

Friends and neighbors also provided support in various ways, such as providing respite so the caregiver could get out, by bringing food and by providing moral support.

Group I

Friends were very supportive. A lot of friends came to offer help. They would bring in food time and time again. Under the circumstances, if we hadn't had so many family and friends helping we would have needed more help from home care.

Friends were very helpful. one friend would come and help with meals for the kids and do the grocery shopping. Her husband took the boys out one night for supper just to give them a break. They were just wonderful. She even did the housework and the laundry. Friends and home care helped the most.

She had lots of old friends she used to phone. There were a couple of other neighbors that used to help out but they were all getting up there in age so it was hard.

The people in the seniors apartment block were really good to just drop in especially if they knew none of the family were around.

She got a lot of cards and phone calls - that was better than them coming. She could just lie and talk to them on the phone then. She had said she didn't want a lot of people to come.

Group II

Some caregivers in Group II found friends and neighbors more helpful than did others.

The neighbors here in the block were not really helpful.

The neighbors all helped out as much as they could but then she got to the stage where she didn't want to see neighbors, friends or anybody else and I think they felt a little hurt but that was her wish.

The neighbors were good. They did what they could, just talking to me and they would bring in food and would come and visit. It was moral support.

She had friends that would come and visit her and they would bring her meals too.

There seemed to be so many people around, even at the hospital. So much so that at times he was wishing nobody would come.

By the first of October he no longer wished people to come to visit. Immediate family it was good.

The neighbors and friends came in a bit so I could get out.

One of the neighbor ladies volunteered to go and sit with her at the hospital so she stayed until 11P.M. and then we had the Nightingale Nurses stay for the night. There were five or six ladies volunteered to go and sit with her in the evening

When her friends would visit I would ask them to stay for an hour and then I'd take off.

Friends and family did not help out very much.

At that time I had a quite a bit of company. In fact I had far too much.

The neighbors were very good. They brought baking and things. Just when you were thinking when will

I ever have time to do some baking they would come along with some more.

5.5.3 Palliative Care (Home Care)

Palliative Care and Home Care have been used as one and the same throughout the paper. All of the clients who were being cared for at home had been admitted to the Palliative Home Care Program, therefore the terms are used interchangeably. The terms client and patient have also been used interchangeably.

In some situations the Palliative Home Care Program was only involved for a very short period of time whereas, in other situations the Palliative Home Care Staff had been going on a regular basis over a period of time and provided various services. Some of the services provided by the Palliative Home Care Program include nursing, homemaking, meals on wheels, social work, occupational therapy, physical therapy, laundry, oxygen services, equipment and supplies. The services most frequently referred to by the respondents were nursing, homemaking and equipment.

During the time many of the caregivers were providing care to the terminally ill family member at home there was a temporary freeze on the home care services and some found it difficult to gain admission to the program at that time.

Group I

It got to the point we just couldn't handle it any more. Mom had to have someone here all the time. There was a freeze on home care at this time and they said they weren't taking any more people on. The next time I called back they came quite quickly. They were to start home care the day Mom passed away.

When it was really desperate was when I thought I wasn't going to be able to get home care because of the freeze. I had to have it. I had to have something because at that point he wanted to come home. I was just fit to be tied. They suggested private. When I called them you could tell nobody wanted to do it. I didn't know what I was going to do, then home care called and said I could have home care. I just burst into tears, I was so relieved. I knew I could quit my job but I didn't want to. I needed my job. If I hadn't got home care I would have quit my job. You do what you have to do.

Group II

I had phoned for help and they said there was a freeze so I gave it up. I thought there was no use. I never had any help. I did it all myself until the last four days when the doctor had phoned Home Care and asked them to come. I hadn't been able to get out to do shopping or if I had heavier things to buy I had to have my husband along to do the lifting because I just couldn't. A year ago I was in a back brace.

I just wish we had had home care earlier. The home care co-ordinator was going to send in somebody twice a week so we could get out because she could see we needed to get out. I was tired and I worried. We found home care a real help when they came. They sent bandages in and she wanted to send the hospital bed but it was difficult to put the bed up in the room so she said she would send sheets in anyway and they would pick them up for the laundry. Once they sent me the bandages I could just throw them away, otherwise I was having to wash all the time. The home care also sent someone to stay the night. I'd advise anyone else to be sure and get in touch with home care because it is a real help. I wish we had had home care earlier, it would have made it simpler for all of us.

Other caregivers found they were able to be admitted to the Palliative Home Care Program but at times their service was restricted due to restraints on the program.

Group I

Home Care came once a week and gave her a bath. They never did increase her service because at that time they were cutting down. I guess we were lucky to get that much service.

Group II

The Palliative Care said they would send someone in but only at 11 P.M.. This was not satisfactory as I felt the only way I would get a night's sleep was to go to a friends house, but it was too late for me to go at 11 P.M..

I am all for that staying at home but I thought the home care was a little short of help. It was a little hard at times to arrange for help because they were short of staff.

I could have used more help at that time but it wasn't available. Funding was a factor. Then they started cutting down on the night bit. It was originally 9 P.M. and then they started cutting down to 11 P.M. until 8 A.M.. That made it pretty tough on me because I would have to stay awake until 11 P.M. and my health was pretty precarious at that time. The services were excellent but we could have used more time, especially in my case when I was an invalid as well, but somehow or other we survived.

In spite of the freeze on the home care services over the summer, the Palliative Home Care Program provided a great deal of support for many of the clients and caregivers. Supports were given both physically and emotionally.

Group I

The home care assessor came when we called and discussed the program. They then came every week to take her blood pressure and check her abdomen. It was only maybe 15-20 minutes but I will tell you there was no better reassurance in the world than this. They would talk about diet and make suggestions. When we would have to call the home care nurse she was here in 15-20 minutes - I mean this was service - I'm sure they can't do this all the time.

These weekly meetings were so reassuring - this was so much better than every 2-3 months with various doctors. They would know what to ask and they would know what to say if you raised something with them. We felt very reassured. I think it was marvelous. One night, the last day before she died, she was in bed - I was upset and sitting up late. I went in and her breathing was very laboured. I called home care and she was here in 15 minutes - this was at midnight.

She died the next morning somewhere between 5:30 and 7:30 A.M.. When I went in the room in the morning she was not breathing. I called right away to the home care and the nurses came right over. She was so good. She just sat with her arm about me. She took right over and called the doctor and the funeral attendants. She did everything that had to be done.

The last week the nurses were here every 3 hours using an anti-seizure drug.

The homemaker help was most helpful. The nurses answered a lot of questions and A. always had a lot of questions so that was most helpful. Things never seemed to happen during regular business hours but with home care you could call them at any time. It was very supportive that home care were coming every day. If we had realized how helpful they were we would have got in touch with them a lot earlier. Without home care we would have been forced to take A. to the hospital.

She likely would have had an easier time with home care. She wouldn't have had to spend so much time in hospital because they would have seen things that could have been corrected earlier before they got too far advanced. With home care

coming earlier it may have meant fewer hospital days the last 6 months which would have made for better quality of time.

Home Care was so good. When things went wrong they just came and took over. They were always there when you needed them. I think the Palliative Home Care Program has got to be the best program that there could be. It was so supportive. There is no way I could have managed without them because even though I was willing I needed that medical backup because I don't know what to do and they could come and reassure me about this and that. Otherwise, I couldn't have done it because I would have never been sure just how he was medically.

They were just super. They just leaned over backwards for us. They were just tremendous. They made him comfortable, they came and bathed him and shaved him, they brought him a commode and things for the bath, a ramp for the doorway and a wheelchair. I didn't know there was that much help available. It was just wonderful.

We just couldn't have done it, we wouldn't have known how to go about it if it hadn't have been for Palliative Care and knowing there was a nurse that would come within half an hour at any time, day and night. That really made a big difference.

Whenever I needed anything from home care I could call and they were right there. I thought we would have enough oxygen to do us over the weekend and we didn't so I just phoned and they were there within hours. We never wished for more services or supplies. They were all good.

It seemed the home care was the support many family members needed to rally around. Many felt anxious about being there alone. If you thought you were on your own it would be horrendous. Just knowing the home care was there gave you the moral support you needed.

Many in Group I called the nurse at the time of death and found her to be very prompt and to be able to

provide the support needed by themselves and their families.

When he died we called the nurse and she was here almost right away. She phoned the doctor. She stayed and made tea for us. They were really super. Anytime we needed the nurse all we had to do was call and they would be right here. That's what made it so nice.

Having the nurses and the homemaker come was a Godsend. It just seemed to take a load off your shoulders. A. passed away at one in the morning. I phoned the home care and the nurse was here shortly after and she called the doctor.

The only thing I had on my mind was to make her comfortable because it was in the bathroom that she died. She was so heavy. I couldn't get her back to bed so I layed her on the floor. I phoned the home care and I phoned the doctor and they both came.

Group II

Group II caregivers also found the Palliative Home Care services to be most helpful.

I was very pleased with the home care. Anything that we needed they were there. The wheelchair, the walker, the commode, the bath stool, the sheepskin and the oxygen tank. All her meals on wheels and everything was paid through home care so that really helped.

I don't know what I would have done without the home care. They helped me in so many ways with him, helping do things for him and being there for me. They were there when I needed them. They were here every day. They got oxygen, the waterbed mattress, the foam, the walker, the wheelchair, a raised toilet seat and a bath seat. They would come and bath him. At times the nurse would come and just talk to me and tell me different things what might happen. What to expect if he did die at home. She explained everything about what was

going on. It was a godsend that she was there.

I don't know how I would have handled it if it hadn't been for Palliative Home Care. I think all the services were here that I needed for him. Anything I needed they had a way of getting it for me. I didn't have to worry about doing something because if I didn't get it done they were there to help me do it.

Just a call to Palliative Care and they were here instantly. I couldn't reach a doctor that quickly. Sometimes the doctor would say, "I will be around later in the day" and we never would see him. The nurses were so understanding.

Home Care started coming in August. He was in and out from hospital so much for I.V.. When he got dehydrated he would get confused. One day I called the home care nurse to come and help because he was confused and he wanted to get out of bed. I thought he might overpower me. I called the home care nurse and the next thing I knew she was here. She was wonderful. That time she said, 'He is so dehydrated we really must take him to the hospital,' so we did. She was so good. I can't say enough good about her. It was just wonderful to know there was someone you could call day or night.

If I hadn't have had Palliative Care there was no way I could have kept him at home for as long as I did. They started coming in September. The nurses and the social worker came regularly. I can't say enough good things about the Palliative Care people. They were just super. He really liked them. They are just special people. They know how to deal with dying people, how to treat them and talk to them, what to do for them.

I wasn't sleeping that well at night and neither was K. so one night the home care nurse said, "I am going to send you someone to sit with him for the night." I just went to bed that night and I slept all night. I felt like a million dollars the next day. Home Care did send someone the night we went to the play. The first girl he was very receptive but the one who came when we went to the play he was not too receptive. She was very young.

If the nurses hadn't come I wouldn't have been able to manage. Home Care was really the only help

I had. Friends and family did not help. The home care worker used to come and sit once in a while, once or twice a week, so I could get out during the day or have an evening out.

I was just overwhelmed with the service. I wasn't used to it - when they came with equipment they would set everything up. They just didn't bring it and leave it. Anything that we wanted or requested we got it. When the girls from home care would come twice a week in the mornings that would allow me to get out. They were very good. They had an excellent staff this home care.

I knew that the home care would come. All it would take is a phone call and they would be here. I phoned the home care once at 3:30 in the morning and they were here by 4A.M.. The service was just great.

The home care used to phone and see how she was doing. This helped a lot because often you just felt so alone. I was impressed with the Palliative Care. Without their support it would have been pretty hard.

I was so lucky that home care was available to us or I just wouldn't have been able to do it. It was the physical support and the mental support. They were far more help to me than my own family was I could tell you that.

Others felt home care was not as helpful as they might have been.

Home Care used to send the home helpers and I personally didn't feel they were trained well enough to sit with V. as sick as she was. That's about the only thing I would say I was disappointed with with home care.

Home care came to show me what to do but provided very little care. I just found it impossible to lift him.

5.5.4 Physicians

Some caregivers found the physician to be very supportive while others experienced frustrations.

Group I

The doctor was in favor of her remaining at home until death. She found it easy to talk to her family doctor. When she passed away we phoned the doctor and he came to the house.

Our family doctor was very helpful. If you called her she would call you back within 5 minutes.

The doctor would stop by even if in the area.

We had a doctor that was super and was here any time we needed him. In fact, he was here when J. died. The doctor knew he had been low in the evening and returned the next morning and stayed until he died. Often he would just come on his own even when we didn't call.

When she died we phoned the doctor right away and he came right up.

The doctor came every day towards the end. She gave us her private number and said we could call her any time.

He didn't talk to me about dying but he did to his doctor. His doctor was very down-to-earth and would come out at night to visit and would talk to him a lot.

Towards the end the family doctor was readily available but earlier in her illness he was not as available. The doctor had been in the night before and he said if anything just to phone.

Toward the end her breathing was getting very shallow and I phoned the doctor and told him I thought my wife was dying and he said, "What the hell do you want me to do about it?"

Group II

It seemed that the caregivers in Group II expressed more discontent with physicians than did the caregivers in Group I.

I took her every three weeks to the doctor but at the last I couldn't get her up the steps. This was when her legs became very big and began to drain. So, then I phoned the doctor and I told him. "Well," he said, "I don't make house calls but tomorrow after I go to the hospital I will come in the afternoon." He said she should be in hospital but there wasn't any room.

Those doctors make me so cross. He started vomiting blood so I took him to the emergency and he told him it was from taking an aspirin so instead of keeping him in they sent him home that night and he started vomiting blood again. The next day we took him back by ambulance.

The doctors never came to the house. One day he was so dehydrated and we thought he should go to the hospital so we called the doctor at 11:30 A.M. and he said he wouldn't be able to come and see him until after his hospital rounds at night but if we brought him to the office he would see him there. So we took him there and we sat in the office for a while. It was really embarrassing to have such a sick man sitting amongst the people. He didn't have the strength to sit up so the doctor saw him and told us to take him right to the hospital and he was admitted.

The doctor only visited once. The home care nurse had requested he visit. He never really did anything. We worked totally with home care.

The doctor wouldn't visit at home.

Our family doctor wasn't very sympathetic toward her condition. He wouldn't give her pain killers the way we felt he should. She requested it a few times and he wouldn't give it to her so we changed doctors. The first thing this doctor did when he came was to look at her medications. He gave her some new prescriptions and she improved dramatically. We were even able to get her around quite a bit after that but then it started going downhill.

The doctor never did come to the house.

There were also reports from Group II caregivers which demonstrated other doctors were very supportive.

The doctor visited at home a couple of times and was most receptive.

The doctor had said we could call her any time. She was very supportive and had said she knew V. was much happier here than if we had put her in hospital. I think with having her support you enough to feel that if you really needed her in a hurry that you probably would have got her.

The doctor was very supportive and would come when I called. That is something that would help anyone is to have a doctor who can be your friend and that you can talk to.

The doctor came to the house regularly. He said any time of the day or night we could call him. That was a real support - that helped the most to know you had that kind of support. He was wonderful. Even when she went to hospital he used to come and sit with her.

The doctor and the minister were so good. The first time the doctor came he sat and talked to her a full hour.

5.5.5. Religion

Religion is similar to the other support systems in that some caregivers found their religious affiliation to be most helpful whereas others who were members of a religious organization found it was not as supportive for them at that time as they would have liked it to be.

Group I

Religion was very important - church, minister and friends were very supportive. Our minister and his wife were here often. His wife would come often and just sit with her. She liked to see them come. When she passed away we called our pastor and he came right away. He was very helpful.

Faith helped a great deal. The minister and others from the church visited often. One of the ministers that had visited came right away when he died.

The minister came every week. The minister came over the morning she died.

The priest came several times and gave him the last rites 4 days before he died.

Her faith was very important to her.

The minister didn't come too much at the end. She never really asked to see a minister.

She really didn't get much support from the church. It's such a large parish that people just seem to come and go. It's not like a small town where the priest is part of the community. The minister would pop in for communion once in a while but it was a different one each time so it really wasn't that much help.

Group II

She had to go to church every Sunday. That was her whole life. The priest came to the house and gave her communion.

The minister came very often. He would be here sometimes until two in the morning. She found that a real help.

The priest came often to visit even after he went to hospital.

The minister and other church members were very supportive. They sometimes visited twice a week.

The minister visited at the hospital and he was the first one I contacted when she died. He just sort of took care of things.

V. was very religious and was a staunch supporter but they never visited once since she came to stay here. I realize the ministers are very busy but they also knew how very ill she was. He did come to see her in the hospital and he didn't even offer a prayer.

I had phoned a minister from the United Church, he came once and he never came back. He didn't do anything. The minister at the hospital was very good. He would often visit him at home and I asked him to do the service. He did a lot of talking to me.

I believe in God a lot. God has his ways. I'm a very religious person. That's how I got through everything.

5.5.6 Others

Social Work, Nightingale Services and pets were three additional supports which the caregivers found to be helpful. Several of the caregivers mentioned that the social workers at the cancer clinic were most helpful.

Another service that several caregivers in Group II utilized was the Nightingale Nurses. This is an independent nursing group with a fee for service. The Nightingale Nursing Group was established by a group of nurses who recognized the need for a comprehensive, professional home and hospital nursing service in the community. Five caregivers in Group II referred to the fact that they had hired a nurse to be with their family member once they returned to hospital. Only one had reported that they had hired a nurse to come in a night while the terminally ill relative was still at home.

Another area of support which was reported by three caregivers was that of pets.

His dog meant so much to him in the last three years since he was sick. He didn't mind me being alone when the dog was here.

I have really found the pets are a big help and good company.

She was in her house with her family and her cats.

The presence of pets was apparent in several homes but not sufficient data was obtained to provide any comparison between the two groups.

5.5.7 Summary

Family were found to be very supportive. It seemed if family members were able to come and stay with the terminally ill family member and the caregiver during those final days that the patient was more likely to remain at home to die. Nine of fifteen caregivers (60%) in Group I reported having family members who were able to come and stay at that time. Only two (13.3%) in Group II reported having family members that stayed - in one situation the family members were living at home and in the other the daughter was not able to stay during the last month.

Three in Group I (20%) reported having family members who lived in Saskatoon and were able to come and go frequently but where they did not live in during the time of caring for the terminally ill family member at home. Six of fifteen in Group II (40%) reported family members would come and help out whereas, seven (46.7%) reported not really receiving much help from family. Two in Group I (13.3%) reported not having any family to help out and one (6.7%) reported friends being much more helpful than family.

The majority of the caregivers in Group I (80%) reported that family had been very supportive and many felt they could not have done it without the help of family, whereas Group II did not report the family as being so supportive.

In the section on previous health care experience (5.2.9) it was reported that five of the caregivers in Group I had worked in a health related field while only one in Group II reported health care experience. In Group I six of the caregivers reported having family members with health care experience who were helping while only three (20%) in Group II reported having family members with health care experience.

It seemed those families who did not have the support of other family members found friends to be most helpful. In many situations it seemed the patient and the caregiver preferred just close relatives and a few close friends to visit. They did not really appreciate many friends visiting but did appreciate the phone calls and cards.

Over the summer months, during the time many of the respondents were either receiving care or were requesting help from home care for the first time, home care services were frozen due to financial restraint, thus limiting the

number of people that could be admitted to the program. This factor added additional stress for the caregivers who had been managing but now required additional help in providing care for their family member at home.

Palliative Care was identified as a source of support, but since it was a service equally available to both groups, it was not considered a factor in determining whether the patient returned to hospital to die. The question remains whether those who died at home would have returned to hospital to die, as well, if the time at home for both groups would have been shortened if the service had not been available.

Some caregivers felt they could have managed without the Palliative Care Team, but knowing they were available day and night was most supportive. Other caregivers reported that without the Palliative Care Team they just would not have been able to continue to provide care for their terminally ill family member at home.

Some of the advantages of the Palliative Home Care were:

1. The emotional support during the time the caregiver was providing care as well as at the time of death.
2. The home care nurse would come so quickly when called (15-20 mins.) day or night.

3. They answered many questions and provided suggestions which were helpful to both client and caregiver.
4. Being available at the time of death.
5. Providing treatments such as the administration of an anti-seizure drug, enemas and dressings.
6. Providing assistance with bathing, skin care etc.
7. Supplying the equipment as needed, for example wheelchairs, commodes and oxygen.
8. The homemaker was also seen as being very helpful as they helped out with the household tasks as well as providing respite for the caregiver.

Both groups spoke highly of the Palliative Home Care workers - there were few negative comments about the service or the staff. One of the concerns expressed was the fact that some of the homemakers who came to provide respite especially at night were very young and as a result did not offer much support to the caregiver. It was also very interesting to note the trust relationship that developed with the regular home care staff but the feeling of insecurity when their regular nurse or homemaker was not there. It seemed very important to the caregivers that they get to know the workers and that the same workers return to provide the care whenever possible.

One of the caregivers in Group II seemed to sum up the feelings of many of the caregivers, "I can't say enough good things about the Palliative Care people. They were just super. They are just special people. They know how to deal with dying people, how to treat them and talk to them, what to do for them."

There were varied comments in relation to physicians. Some found them to be most supportive of the patient remaining at home, they were available when called, some left their private numbers so that they could be called day or night, others would come and visit and often would stay and spend time with the family. In Group I only two (13.3%) reported that the physician had not visited in the home more than once, whereas in Group II, six (40%) reported that the physician had not visited more than once. The comments made by Group I caregivers were more favorable than the comments made by Group II.

Some of the caregivers in Group II reported that physicians would prefer not or even refused to make home visits. If they did agree to come to the house, sometimes they would not come at all or they would visit several hours after they were called, sometimes not even until the next day. Many felt they did not have the support of their physician that they would have liked whereas others felt very fortunate to have a doctor who cared. One caregiver

commented, "The doctor was very supportive and would come when I called. That is something that would help anyone is to have a doctor who can be your friend and that you can talk to."

Religion was also found to be very helpful for some, while others felt disappointment in the support they received from their church and their minister. Frequent visits and support at the time of death were found to be most supportive.

One of the additional community services which was used by five (33.3%) of the families in Group II when their terminally ill relative returned to hospital was that of the Nightingale Nurses, an independent nursing service. This service was only used by one of the families during the time the patient was at home.

All of the above mentioned supports were of benefit to individual patients, families and caregivers in different ways depending upon their own particular situation. Caregivers called upon personal strengths they had employed over the years as well as on additional formal and informal supports as they were available, in order to sustain them in their caregiving role.

5.6 Decision Making

During the illness of the client, decisions had to be made in relation to further treatment as well as to whether the client was to remain at home or remain in the hospital. For some families these decisions required a great deal of discussion with various people whereas for others the decisions were straightforward, as they felt there was only one decision which would be appropriate for them. Decisions tended to be made by the client, the family, and by others such as the physician, the home care nurse or those at the hospital. This section will be divided into two categories - those decisions related to further treatment and those related to whether the client would be cared for in hospital or at home.

5.6.1 Decision Making about Further Treatment

Group I

The doctor came up in the afternoon and said he had an infection and I had three options: I could either have him admitted to hospital or take him to emergency and have his medication given there or else I could keep him here. I said I wanted to keep him here because he didn't want to go to hospital. I found it much easier having him at home and looking after him than him being in hospital and having to go back and forth. I found that much more tiring.

Even the week before she died the doctor said he wanted to give her another treatment which I did not want. Right then I felt this was research and I said I wouldn't be able to bring her in because

she wasn't strong enough and if he would like to see her he would have to come here.

Even at the last admissions we would have preferred she not go into hospital. It was the family doctor who encouraged her to go to hospital.

The hospital would have done everything in their power to keep her alive and we told them if it was up to us we didn't want anything done.

He had been so ill with his chemo that the doctor decided to quit the treatments. He said this was not quality life. If it had been up to K. he would have kept going with the treatments until they killed him.

When she was in the hospital the last time, her bowels still didn't start working after that last operation and the doctor wanted to take some more tests and operate again and she said no. He said to her, "What do you want to do? Go home?" and she said "yes."

It was her option if she wanted to go through the cancer clinic. She decided no. We didn't pressure her. That was her decision.

He said, "You are going to have to take me home to get a tube put in" and that amazed me because I used to work in a nursing home and I used to talk about tube feedings and things like that and he said never ever would anybody ever do that to him. And I always felt that way about me too, if I have to stay alive like that give me a little dignity and let me go. I couldn't believe he was asking for a tube.

She thought she would have liked more treatments but the cancer clinic said they didn't advise it - they felt it really wouldn't help any more.

Group II

The family had decided we didn't want any life support because we knew it was just going to prolong it. The doctor agreed with us but suggested just a wee bit of life support to make her comfortable and gave her some intravenous but she never regained consciousness.

Then my husband decided to take the chemotherapy. The doctor told us it might make it worse but he wanted to give it a try. I didn't want him to take it. Anyway, he went and took his chemotherapy. He was fine for two days but oh, did he get sick after that. I spent most of my time with him at the hospital for the next three days. He decided then that that was it. He didn't want anymore.

We felt if he had to suffer like this for a long time we didn't want that. The doctor had asked me if his heart quit if I wanted them to bring him back to life. I couldn't make that decision so I got the kids together and we talked about it. The kids felt too that he had suffered enough and thought we should let him go. Because he was so bad I just couldn't see bringing him back to suffer some more.

We knew it was just a matter of time until he was going to die and none of us wanted him on support services just to prolong the agony he was going through. When you watch somebody die like that you don't wish for them to go on.

She didn't make the decision to quit radiation treatments, they just stopped.

5.6.2 Decisions made about remaining at home or in hospital.

Many of the decisions to remain at home or to return home following hospitalization were made by the patient and caregiver. What they were looking for from others was the

support they needed to be able to do this. All of the patients in Group I expressed a desire to remain at home whereas, in Group II, four (26.7%) expressed a wish to return to hospital.

Group I

She mentioned a long time ago - she said, "When I get to where I can't get around I would like to stay at home."

Because our father died in hospital, we wanted our mother to remain at home as long as possible. Once we had her home we just cared for her and if she was going to pass away here that was fine. Now we feel we would want it no other way but to die at home. The whole family was agreeable that she should die at home.

It was her request and ours that she come home at that time. They would have preferred to keep her. Her electrolytes were still low. She stayed two days longer than she had expected to but she insisted on coming home.

I wanted to try and bring him home. He was to the point he really didn't care if he came home but I wanted him home so I pushed ahead. When the doctor discussed his going home K. shared his concerns about how hard it would be on me and the boys. The day I went to get him he was really anxious to come home. This made me so relieved because I thought maybe I was doing something he didn't want to but it was hard to know. I knew how he hated hospitals, I thought he must want to be home better than that and so we brought him home.

The last couple of weeks were very hard. I had come to terms with the fact he would die at home. The kids had come to terms with that. I had asked them when he took that sudden turn - I said, "Okay, we said if anything like this happened we would discuss it and we would be open with each other about what we wanted to do and how we felt. If we are going to put Dad in the hospital we have

to do it now because we might not have another chance to make this decision" and they said, "No, we want him at home."

But you know, you can never think in advance what you will do because I had people pushing me a year before to decide whether or not K. should die at home and I said there was no way that I could make that decision, that it was K's decision, whatever he feels good about. They felt we should be prepared, I told them, "I can't even bring it up let alone discuss it. I just can't make myself say it." I said, "I could never make that decision." I was warned that if I didn't discuss it with K. I may be forced to make that decision because he may not be able to. But I still couldn't discuss it because I couldn't even say it. In the end there was no decision to make. That was the only logical thing to do. That was just the right thing. In fact, before that I would have tended to think it would have been the other way.

Just over a week before she died the doctor came and he said to her, "Do you want to go to the hospital?" and she said, "No." Her daughter was here and she took her to the bathroom, then the doctor asked me, "Do you want her to go to the hospital?" and I said, "No, as long as she doesn't want to go. I want to have her here too." I said that if it was going to be better for her I would let her go but I didn't want her to go, so he said that was fine. I knew she wanted to die at home.

They wanted to put her in hospital to drain the lungs. She made me promise her not to send her to hospital. She didn't want to go back to hospital.

Nobody really became anxious about her dying at home. I think it was partly the way she had accepted it. Everybody just felt that was her decision.

Everyone was very realistic about what was happening and everyone accepted it. She had been in hospitals a lot and really didn't care to be in hospital. She seemed to feel a great sense of security in being at home knowing that things were still being looked after. We had said to her, "Anytime you feel you would like to go back to hospital, if you want someone to look after you more than we are, just say the word" so she knew

she had the option but never once did she say she wanted to go to hospital. I wondered how she would feel as she got sicker but when she was in hospital in February she just couldn't get out of there fast enough.

He was just petrified of dying in hospital. He wanted to come home. I was nervous about bringing him home because they hadn't even had him up walking in the hospital, but we managed.

That was his only wish, the only request he had, that he wanted to stay home - "Don't put me back in the hospital." He had very few requests and this was one of them and I was determined to honor it. I got a big lecture from his aunt in "That's what hospitals are for" and "You've done all that you can do." He didn't complain about anything and when he only had the one request I thought it was a very meager request. "What can they do for him in there that I can't do here?" "Well," she said, "he should have been having I.V." And I said, "Wow, there's one thing we don't want to do and that is prolong this." You don't want to lose them but you don't want to see him suffer.

She didn't want to go to hospital. The family all accepted the fact that she wanted to die at home.

He wanted to stay home and I wanted him at home but the doctor suggested he admit him and I asked if there was some special care that he would get in hospital that he wasn't getting here now and he said, "No, but you can't go on like this. You have to have help." He said if I would agree to home care then it would be fine for J. to stay here.

I don't think the fact of care entered my mind. I certainly didn't want him in hospital.

She didn't like being in hospital. She wanted to be home. I felt that if it was her wish that she be at home - we knew we would be together then and we knew it was only a matter of time.'

Two or three nights before she passed away the doctor from the clinic came in and he said to her,

"Should I put you in hospital?" and she said, "No, I want to be here at home." She accepted her condition. She said, "If it is my time, it's my time." At the end she even took the oxygen off. My daughter wanted to put it back on and she said, "No, this is it. I'm going home."

Group II

Many of the decisions which were made regarding the patients return to hospital were made by the caregivers. About half of the caregivers in Group II (7 out of 15) expressed anxiety about the patient dying at home and said they preferred that their family member return to hospital to die. There were others who felt they could just no longer manage and that the patient would get better care in the hospital. As well, some of the doctors encouraged the caregiver to have the patient return to hospital.

It bothered me once she was in the coma. I just couldn't look after her. The home care nurse phoned the doctor and he suggested we keep her until morning but the home care nurse told him it was the family's wishes that she go to hospital. I just didn't feel I could manage anymore. I thought it better she be in hospital.

After one week of respite in hospital they told him he could go home. I told them I was unable to care for him as he could not walk and I could not lift him. They said they would get an ambulance to send him home. They told me I would have to put him in a nursing home or take him home. They told me, 'The hospital is no place for people like that. Only when we can do something for them will we keep them.'

The doctor was here and asked me, "If she passes away where do you want her to be - at home or in hospital or in the nursing home," and I said

"Anyplace else but at home. I don't want her to go at home." So then he said, "If you want it that way then we better look for a bed because she can go just any time."

For a while she was very serious that she wanted to go to hospital. She thought she would get better care there. But she was only there for two days and she said, "I want to go back home." Our doctors wouldn't allow this. They said, "It can't be. We can't do it. She is too far gone."

I would have had to have the oxygen, the I.V., the hospital bed and I don't know what else I would have needed to have him here. I just couldn't have had him here.

I felt if I had seen her die in this room I could never stay here. I had never experienced anything like this before.

I was scared to have him home because I didn't know how I could handle him. How to handle the whole situation that he might die at home with me and I was so scared of this. I should have got him home sooner but I didn't. So then finally I realized he really did want to come home and I thought no matter what, I've got to have him home because they told me he could have a good summer, and maybe up until fall. The social worker at the cancer clinic was very good. I had told her I was scared to bring him home and after I talked with her I then realized I should have him home. I think I really wanted him home it is just I was so scared to bring him home.

When he could he wanted to be at home. When he was in hospital for a few days then he would want to come home. In August, he went to hospital for the last time. The doctors felt that if he was in the hospital he would be better off.

If I could have had my daughter longer I would have kept him home longer. It was just impossible for me unless we would have gone to a full time nurse. I would have needed someone here all the time. He was getting so weak and I was so afraid he would fall.

I think we could have gone for a little extra professional nursing but it was really decided between the Palliative Care and the doctor when he should go to hospital and how long he should stay there. We had no say. When the doctor said he could come home we took him home.

It wasn't my decision to put him in hospital. It was Palliative Care. The home care nurse said the time had come, he had to be in hospital.

Before she didn't want to go to the hospital but at the end she wanted to go. She used to get very anxious when she choked. At the last I just couldn't cope with it any more. They could take care of her better there. At the hospital they used suction and that helped.

If you were to keep her home longer you would have needed to be with her steady. If someone would have come six or seven hours a day it would have really helped. If the nurses would have come to the house they would have been able to do for her here what they did at the hospital. I just got too tired myself to do anymore. I just couldn't.

I think he didn't want to die here because he knew it would be hard on me. I wouldn't have wanted him to die here. If he had of, I never would have stayed here. I would have never made it. It was really better he died in hospital.

It was just awful before he went to hospital. He had no control about going to the bathroom. He'd be here at the table and he couldn't get to the bathroom, that was terrible. Then his back was sore, the cancer had spread. I just couldn't manage him myself. That was terrible. Then he got worse and worse. One night he threw up blood all night and that is when I thought he should go to the hospital. I called the home care nurse at midnight and the ambulance and got him over there. He never came back.

I actually felt at the time I should have kept her home but the doctor thought they could give her

better treatment in the hospital with the intravenous and support. She wasn't in hospital quite a month before she passed away.

As I look back now I think I would have sooner kept her home but she had requested that she not die at home. She said, "I do not want to die in my own home. Take me out and don't let the boys see me when I am no longer rational."

She accepted being in hospital and never asked to come home. She knew she was very sick. At the time it was the logical place to be and she accepted that.

I couldn't have gone on any further. I had asked earlier for her to go to hospital and they said, "No way, she was getting better care here than she would have got in the hospital."

My sister and my three brothers wanted to put her into hospital and I didn't. I said, "No way - she is going to stay here as long as I can possibly help her" because I knew, everytime any nurse or anyone came she said how she loved her room and she was just so happy to be able to be here.

They were to bring oxygen that day and I just said, "That's one thing I would be nervous about. I think we should phone the doctor and see what she says." She agreed that we should take her to hospital.

She just went to hospital hours before she died. She just wouldn't eat. The home care nurse came in the morning. I called her because I couldn't get M. to eat her breakfast. The nurse came right over and she said, "I think we better put her in hospital." I said, "I want to keep her here as long as I can because I give her the care that she needs." The nurse was worried about me you know. I said to her, "If you leave her on the basis that I can get a hold of you of she turns much worse." I phoned her about 1 P.M. and my regular homemaker wasn't here so I decided on my own to get a hold of the nurse and she called the ambulance and she went to the hospital at 3 P.M. and passed away around midnight.

Another factor which had an effect on the decision making regarding whether the client remained in hospital or at home was related to concerns about care that was provided in hospital. These concerns were shared by both groups of caregivers, but Group II felt this was their only alternative at the time the decision was made for the patient to return to hospital.

Group I

We just thought she would get better care here and the doctors told us that too - the hospital is so short staffed.

To be honest I think we were able to give her better care here than she would have got in hospital because when you have one girl on a whole ward they just can't come when you need them.

In February she went into hospital. She got very dehydrated. She was in about five or six days and I was really annoyed with what was going on at the hospital and I called the doctor and said, "I think we can do as good for her at home as they are there." She was really weak and couldn't get herself out of bed to go to the bathroom and they were of the opinion that she really wasn't trying. The doctor had told her that as soon as she got her strength back they would get her off the IV and she was really trying to drink all she could possibly force down. He said, "You can go home as soon as you get your strength back a bit." She would keep saying to them, "Do you think you could walk with me for a few minutes?" and they would say, "Well, I'm too busy right now and will come back later." So my husband and I were going up two or three times a day. We just absolutely

ignored visiting hours and just walked in and took her for a walk whenever we could, even if it was just for 20 minutes.

Then one day I went in and she was almost in tears. They had put her in the chair across from the bell and she had been there for two hours. She couldn't get out of the chair. So I said, "That is it. You're coming home."

Group II

I always gave him his lunches. He just refused for some of the nurses and they just don't have that kind of time to spend on one patient.

They don't get the care at the hospital they do at home. You get a different nurse every day. That's what the wife didn't like. She was lonesome.

I wanted her home. She wasn't happy in hospital. The care in the hospital is not that good you know. They are limited with the number of patients they've got. They can't give really personalized care. That's why I wanted to keep her here as long as I could. She started to cry the day we took her back to hospital. She didn't want to go to hospital.

Some of the decision making was as a result of the advantages of being at home seen by the caregiver.

Group I

It is more private at home than in the hospital and much more peaceful. It was especially nice to have the grandchildren because they didn't get to see him in hospital.

He could see the garden from his window and watch the birds.

She would walk in the garden in the morning and then go for a longer walk in the afternoon.

At that particular point you kind of want to be with them most of the time and at the hospital its not really quite possible - I think they had rooms at the hospital you could sleep in but its not the same as being at home.

That's where she had the trouble in the hospital when they wouldn't give her medication when she said she had pain. When we got her home we gave her medication when she said she had pain. She wouldn't take a pill if she didn't need it.

She was very much in control and that is one thing about being at home is that you can call the shots.

My son would hardly come and visit her at all in the hospital but when she was at home he spent a lot of time with her. He hates hospitals.

It was good to have him home because he could look out the window. We had more time together. In the hospital there was always someone there. You also had more control over who visits and how long they stay.

Group II

She was happier here because the family could come in and it was like a family atmosphere. It wasn't like in the hospital so it made it a lot nicer for her and that was her wishes. She didn't want to go to hospital or nursing home. The night before she went to hospital my son and his wife came in and we all had supper together. That night she was a little confused. She didn't want to go to bed and then she finally did and that night she went into a coma.

If he'd be out in the garden, we would go out and she'd sit on the patio and the neighbors would come over and talk. Sometimes she'd fall asleep out there.

It was better to have him at home than to go to the hospital to visit - it is hard to go to the hospital as I like to come home before it is too late.

We fixed up one bedroom for her with a patio door so she could look out into the garden. She really liked her room.

5.6.3 Summary

The concept of having some control over the decision making of the client when at home was mentioned several times. They felt they had some control over decisions as to further treatments such as chemotherapy, physiotherapy, and administration of pain medication. They also felt they had more control over who visited and how long they stayed. By being at home there was the assurance that life support measures would not be used to prolong their family members life.

It seemed many of the caregivers were very determined to somehow manage because they knew it was the wish of the patient to remain at home. This may suggest a great sense of determination on the part of the caregivers who were able to care for the terminally ill family member at home. Concerns about the care received while in hospital was also a factor taken into consideration when deciding where the patient would die. Many of the caregivers were not pleased with the care provided for their dying family member while they were in hospital.

The advantages of remaining at home as compared to being in hospital were part of the decision making which took place at this time. There were advantages to both client and caregiver in having the patient remain at home for as long as possible. Some of these advantages were:

- it is more private at home and more peaceful
- the grandchildren could visit more often
- he could see the garden from his window
- she could walk in the garden
- it allows you to be with them all the time
- control over decisions such as with pain medication
- you can call the shots
- family were more willing to spend time with them that they just wouldn't have been able to if they were in hospital.
- control over visitors and how long they stay
- more of a family atmosphere
- it is very tiring to be going to the hospital every day
- it is much better to have them at home.

Caregivers in both groups reported they were pleased with what they had been able to do for the patient and with the decisions that had been made at the time. Most reported they would have wanted it no other way.

5.7 Caregivers' reflections of their experience:

5.7.1 Group I

All of the caregivers in Group I were positive about their experience in caring for the terminally ill family member at home. They felt good that the person was able to die at home since that was their wish. There was also a feeling of confidence in knowing the care they were providing for their family member was often better at home than it was in the hospital.

In the hospital - if you aren't there- right with her all the time - I would have only been able to communicate with her when I was there whereas, here any time, all evening long or all weekend. I am not sorry at all that she was at home. She wouldn't have got any better care in the hospital - I don't think so. I think we would do the same thing under similar conditions.

I feel sorry for the family members who did not have the opportunity to care for Mom the way we did - we had Mom's last six months. It takes the morbidity out of death when they can pass away at home. You can carry on a more normal life style. Here you are running one house and with visitors coming you would have been running back and forth. She was able to have someone with her all the time. She was just thankful to be here.

Life carried on as usual. That was good. You're not just sitting by the bed waiting. It is also important for the terminally ill patient not just to be lying in the hospital waiting. I read an article that said, - Dying is as natural as being born - and it really made me think.

Dying with respect and dignity - I think that is what you do when you die at home. It is more dignified and more natural. Mom just went in her sleep. It wasn't scary. It was quiet - we woke up and Mom was gone. To me now I wouldn't want to

see anyone die in the hospital unless it was a sudden death.

I shouldn't say I enjoyed it but I considered it a privilege to look after him.

In June in the hospital I thought he was going to die and I just panicked but here I was just calm as could be. I don't know if it was because he was home or what.

I would do it again the same. I never had any trouble going in the bedroom after or anything. About one-half hour before he passed away he made the sign of the cross. I'm sure he had a vision.

If you can have them at home by all means do it. Knowing that he was where he wanted to be and that I could make him comfortable.

No one wants to die but you want to die with your loved ones around you. I myself would want to die at home if possible - nothing against hospitals - they are needed. She wanted to be where she wanted to be and to have her family around her. It is nice to be home. Hospitals are good but it's an institution. Some people wouldn't be able to give the care like we were. The family was so supportive. We would want to do it the same again if the circumstances were there.

It was her wish to remain at home and I think with home care and the three of us here we probably gave her better care than she would have received in hospital. If I had a choice I think I'd want to be at home too. It's definitely hard on the people providing the care but it's also very hard on the patient. You just have to get some extra strength wherever you find it.

Even the kids, you know, they seldom went to the hospital to visit him because it upset them especially the little guy. If it was a nice day they would ride their bikes up there, say, "Hi Dad" stay five minutes and then take off - "because my bikes outside you know." But if I took them up and they had to sit there for goodness knows how long they just hated it. It was very uncomfortable and intimidating. But what I found

at home was that well, the first week he was mobile and I could get him up and he could come out to the living room and would still be able to talk to the kids. But once he was in bed and was really going quickly, J. (14yrs.old) would go in and sit on the edge of the bed and just sit and just look at him. Not say anything but just sit there and he felt obviously comfortable or he wouldn't have gone in and done this on his own and that was time he wouldn't have had if his Dad had remained in hospital.

I would take my breakfast in and eat it in his room. B, our youngest would come in while I was having my breakfast and he would sit and have a visit with us before he went to school and again, he wouldn't have had time like that with his Dad if he was in the hospital. In fact, one day B was leaving for school and I was doing something for K. B. came in to say goodbye and K. called him back and said, "Now you have a good day you little turkey." Those are the things that mean so much now.

As far as K's death goes, I was ready to let him go and if he had been in the hospital the kids wouldn't have seen that, but I think because he was home and they did see that maybe it made it a little better in terms of them. It was easier for them to let him go even though I haven't discussed this with him but you could never wish him to live like that. B used to give his Dad hugs and kisses at night but not at the end - he started to pull away.

I would do it again. It was definitely the right thing to do.

I was always frightened I would walk in and find she had passed away. I had never been that close to anyone who was really sick or dying. It was an experience and actually I was quite pleased with myself because I was really worried if I knew she passed away and then for her to actually pass away in my arms. I couldn't believe how I coped with it.

I think it's good that she died at home, especially when she wanted it that way. I wouldn't have wanted it any other way. One thing I wish I had asked her was where she wanted to be buried. That was about the only thing we had to struggle with after she died.

It has never bothered me that she died here in the house whereas I know some people that just

couldn't accept that. I don't know anything else that could have been done. Anything she wanted we tried to do for her. To be honest, I think we were able to give her better care here than she would have got in hospital because when you have one girl on a whole ward they just can't come when you need them. If I had to do it again, I wouldn't turn away from it at all unless she wanted to go to the hospital.

If I had him here again I would do it all again. If I had it to do again, I never would have taken him to hospital for those two days.

It was stressful but I don't know if it was more stressful than having them in hospital because I know how frustrated I was seeing her in for those five days and I'm sure if we'd have left her there she wouldn't have lasted two weeks whereas she lasted six weeks after we brought her home.

We really felt we were able to do exactly what she would have wanted. As I look back there is not anything we really would have wanted to do differently. I think we all went away feeling we had done the very best we could. We told the people in the Palliative Care Program that it gave us a chance to do our last little bit.

On the whole we were very pleased with the way things had gone. Mainly for the rest of the family. If they had come to see her and then only been able to see her in the hospital I don't think they would have felt as good about it or stayed as long. This way they all felt they could do their bit and it gave them an opportunity to be together for a whole week not just for a couple of hours a day.

It is a more relaxed atmosphere than in the hospital. It is very trying to visit in the hospital day after day and watch them deteriorate. It is bad enough at home but I think it would be worse to see that happen in the hospital.

I think we were both more relaxed at home than we would have been in hospital. You do what you feel like doing. We would sit and watch T.V. together. There were lots of things about the business we could talk about. I don't know if anyone else has this problem but when I go to visit in the hospital I can never think of anything to say to

anyone once I get beyond the 'How are you today?'

It was better at home. His friends could come and see him and I think they were more relaxed here than in the hospital. At home I could be with him day and night otherwise one has to leave to get your rest.

If I had to do it again I would certainly do it that way again because I thought that was the best. She definitely didn't want to go to hospital.

The one caregiver in Group I who would have liked things to be different found that he was able to manage during the time of illness but when when his wife was dying he did not receive the support that was needed;

Toward the end her breathing was getting very shallow and I phoned the doctor, "What the hell do you want me to do about it?" I tried to get the palliative care nurse and I couldn't reach her so I phoned the ambulance. I didn't know just to phone the funeral home. The police came too.

This was the one caregiver who also reported his health was worse now than it was prior to the death of his wife.

5.7.2 Group II

Many of the caregivers in Group II were also pleased with the care they were able to provide and for the time they were able to spend with that person. The same feeling of confidence did not prevail with all the caregivers in Group II as it had in Group I. Several of the caregivers in Group II expressed anxiety in caring for the patient especially regarding choking and coma.

Two of the caregivers in Group II reported it really bothered them when their family member went into coma but felt satisfaction in knowing that that person never knew they had returned to hospital. Therefore, they felt confident they had fulfilled the wishes of the patient. A third caregiver felt very insecure at home and stated it was much easier knowing his wife was getting the proper care she needed. One of the caregivers regretted not being with her husband when he died.

We feel we did what we could do and we carried out her wishes that she could be at home. She never knew she went to hospital.

I'm just happy. After all the things that she did for all of us I was happy I was able to do it. Three of our sisters were here to visit the week before she went to hospital. It couldn't have worked out any better as far as we were all concerned because she just didn't want to go to the hospital and when she did have to go she was not aware of where she was. I have a feeling of real satisfaction for what I was able to do and just knowing the home care nurses were there whenever we called was a real help. One of the home care nurses went to the funeral.

For me, at least, I knew she was getting better care in the hospital. She was getting the proper care she should be getting. That part was easier.

When I had him here I could do things for him myself that I couldn't do in the hospital. The kids could come and go when they wanted to, they could talk to him without anybody else being around. I had time with him myself. I had my doubts when I brought him home. I was so scared to have him home because I had never had anybody that sick so I didn't know how I could cope with it, but God, I wish I had of brought him home earlier.

For the time I had him home I am not sorry. I am really really glad I had that chance of having him home. It was awfully hard going to the hospital all the time and spending all of your time up there. He was in a private ward but it just wasn't a place where you could feel you were together. You just sat there with him. At home here I was doing stuff for him that I could do and if I couldn't do it one of the kids were here to do it for him especially my oldest son. He spent a lot of time with his Dad. He says he has lost his father and his friend.

My one regret is I wanted so badly to be there when he died and I wasn't. I just wanted so much to be there.

I should have taken more help earlier. They kept offering but I just didn't. If I had it to do again I sure would. I just got too weak.

It was really nice we were able to have him home as long as we did. He was only in hospital for a few days and he was asking to come home. That was hard because we knew he wasn't going to be able to come home again.

That she didn't respond to me the way she did at home really bothered me. I often wonder what would have happened had I kept her at home.

It was a good experience. I don't know if I'd want to do it again. It was a growing experience for all of us here. My blood pressure went up while caring for her. It is back to normal now and I feel good.

5.7.3 Summary

The majority of caregivers in Group I felt there was very little they would want to change. Some felt more help from Home Care or receiving help earlier maybe would have been helpful, but felt they were able to manage. Most were

very pleased with the way they were able to conduct themselves at the time of death and felt they would not hesitate to do the same thing again under similar circumstances.

Many of the reflections from Group II were similar to those in Group I in that they had done everything they could and that at the time their family member returned to hospital, that seemed to be the only right decision. They also mentioned that with extra help from Home Care and with getting help sooner maybe they could have kept their family member home longer.

5.8 Present Situation

Many of the caregivers talked about their present situation and what their plans were for the future.

Group I

I am now ready to get on with my life. Sometimes I think gee, it's only six months and I am so eager to get on with my life - but really, it has been two years.

If you think about what that person who has gone wants for you it gives you a kick in the butt to get going.

All our plans for retirement are gone. I plan to move back east now.

I feel like I've gone through a long dark tunnel and I'm nearly at the end.

Many of the caregivers reported that they had been away on vacation since the death of their relative and now felt they were ready to start becoming involved in things again.

I still find the evenings long when you are alone but the days aren't so bad as I can get dressed and go out somewhere. I do a lot of volunteer visiting for the church.

The first few months after his death I was at my daughter's a lot but I feel really close to my husband here and I was missing that. My father passed away with cancer and seven days after the funeral my oldest brother took my mother away for three months. I can remember her coming back and saying, "Oh for God's sake, if anything like that ever happens to your partner stay and face it. Get used to it and then go away." That always stuck in my mind.

I am glad we kept the business, it gives me something to do.

It is very different being single at thirty seven than at seventeen. Where do I go from here? I will just take it one day at a time.

Group II

Those first days were so long - not going to the hospital, but now my days go by faster.

The support group in the field house is very good. I'm getting back to golfing and dancing.

As a matter of fact what I did, and I think it was the smartest thing I ever did, was I did a complete exorcism of R. within the house. Once her

children picked up what they wanted then I just went through the drawers and I burned everything. No ghosts - I had to do that. My quality of life has improved. At first everything was momentous but gradually once I had done, like I say, the exorcism, then I established my own routine with the house. My day is full. I manage to have a hot meal everyday. For me I think I am functioning quite well.

I know at times I have tried to be strong for the kids but it still hurts so much.

Through the day I am okay but I still waited for him to come home after work for a long time.

It is very lonesome. I really don't like going out much myself.

You need to be able to talk to somebody else other than just family.

Where does a single person go. You are starting your life all over from scratch.

Three of the caregivers in Group II spoke about moving and taking up a new residence. For these three caregivers it had been nearly a year since their spouse had died and they were now looking at where they as an individual would want to live and what they would want to do.

Many found families who were supportive at the time of caring for the terminally ill family member at home were still very supportive.

Group I

The family were so supportive and still are. They make me feel like a V.I.P. you know.

A's folks are still very supportive.

My daughter came and stayed a week with me after the funeral.

The children still come often and my grandchildren.

Group II

I talk to my daughter every day, she is a real support.

I have two boys in Saskatoon. One of the boys take me for breakfast every morning. This other son of mine - every other day he has to baby sit with his kids so that day we go to MacDonald's for lunch.

When I had him home here his kids spent a lot of time with him. After he passed away the kids were there for me and they are still there. If I feel I need to talk I can phone them and talk to them.

My daughter has been so good. She just took over everything. She still comes and helps me a lot.

My daughter stayed with me for a week after my husband passed away and my sister and her husband stayed for two days afterward, then I had to learn to be by myself.

It has been really lonely since she died. My grandson has been staying with me during the week because he is going to high school just over here so that is a little companionship in the evenings at least.

Some found their friends changed and many of the friends they had as couples no longer came by.

At that time I had quite a bit of company. In fact, I had far too much. After she is gone I wish

now they would come but it's a completely different thing. Now nobody comes.

My old friends don't really come around much anymore.

Others found their friends to still be very supportive and continue to invite them out for dinner often.

Summary

For each caregiver their present situation was as individual as were their coping strategies during the time they were caring for their terminally ill family member at home. By listening to the caregivers, one is able to better understand what it was like at the time of diagnosis of terminal cancer, what it was like during the time they cared for their terminally ill family member at home and now their feelings and plans about their present and their future.

It is only after we understand the feelings and concerns of these caregivers that we will be able to help others who are facing similar situations. It is also important that we are able to assess each situation in such a way that intervention is introduced as it is required. It is only through appropriate intervention at the appropriate time that major disorganization will be avoided and growth and health will be the result.

CHAPTER 6

SUMMARY, DISCUSSION and RECOMMENDATIONS

6.1 Overview of the study

The purpose of the study was to gain a better understanding of primary caregivers and how they were able to manage the care of a terminally ill family member at home. This study was exploratory in nature and was conducted using a qualitative method.

Specific objectives for the study were:

1. To identify the primary caregiver's self perceived strengths and weaknesses.
2. To identify the reported key factors, including formal and informal support systems, which were influential in the primary caregiver's ability to care for the terminally ill family member at home.
3. To determine whether commonalities exist among primary caregivers who are able to care for the terminally ill patient at home.

The conceptual framework for this study was provided by the crisis theory model. This model included the involvement of an individual facing a hazardous event along with significant others. The model of crisis theory and

intervention provided a view of the diagnosis of terminal cancer as a hazardous event which had the potential for becoming a situational crisis. Other stressors which increased the potential for a crisis situation were: lack of supports both formal and informal as well as the physical and mental characteristics of the patient and caregiver. Internal and external resources were influential in determining the coping strategies of the caregiver.

The crisis theory model allowed for growth and health to take place along with the resolution of the crisis. This seemed to be the outcome indicated by many of the caregivers in both groups. Caregivers in both groups reported feeling good about what they were able to do for their dying family member and in many cases felt it had been a growing experience.

The interview guide which was utilized during the study was developed based on the conceptual framework, the literature review and the clinical experience of the researcher.

The participants of the study included thirty caregivers who had cared for a family member who had been diagnosed with terminal cancer and had been admitted to the Palliative Home Care Program in Saskatoon. Fifteen of the participants had cared for a terminally ill cancer patient

until death occurred (Group I). Fifteen of the respondents had cared for a terminally ill patient at home during their illness prior to the patient returning to hospital to die (Group II).

6.2 SUMMARY OF THE FINDINGS FROM THE STUDY

6.2.1 Self Perceived Strengths and Weaknesses:

Some of the strengths which were perceived by the caregivers were:

1. Self discipline - "In a situation like that you say this is the way it is. There is no point in breaking down. It wasn't going to help the patient." "I just took it like an alcoholic - one day at a time because I never knew what the next day would bring."
2. Ability to work under stress - "It seems I work better under stress, I just didn't seem to get tired."
3. Determination - "you get that inner strength from somewhere and you are able to carry on." "My physical health being what it was, there wasn't one day from the beginning of his illness that I wasn't able to go from morning until night."
4. Acceptance - "we were prepared and if this was the way it was supposed to be."
5. Willingness to provide care - "It didn't bother me to give the care. Bedpans etc. didn't really bother

me." "I was giving feeding and medication by tube as well as giving insulin four times a day."

6. The desire to fulfill the last wishes of their dying family member.

7. Self confidence in the fact that the care they were providing for their terminally ill relative at home was just as good or better than what they would receive in hospital.

Some of the weaknesses which were identified throughout the interviews were:

1. Some expressed a feeling of helplessness in the fact that their family member was dying and there was nothing they could do.

2. Others found it very stressful when the patient didn't want them to go out.

3. Difficulty accepting their family member was really dying.

4. Anxiety was expressed by some caregivers in Group II in relation to providing care at home. "I was tired and I worried. You are always afraid of something happening to them. The minute she was up, I'd be up because I was always afraid of her falling and breaking a bone or something."

5. Several of the caregivers in Group II expressed anxiety about the family member dying at home. Seven of

the caregivers (46.7%) indicated specifically that they did not want their family member to die at home.

6. Health problems of the caregiver - in Group II eight out of fifteen (53.3%) reported having more than one health problem. Some of the health problems identified were back problems, nerve problems, arthritis, and heart problems.

6.2.2 Formal and informal support systems, which were influential in the primary caregiver's ability to care for the terminally ill family member at home.

According to Caplan (1964), the essential factor influencing the occurrence of a crisis and the ability to cope with it is the resources available to deal with the crisis. Lev (1985) suggests, "The help or hindrance received by others - professional caregivers as well as friends, family and community supports - may make the difference between acceptable adaptation and maladaptation to the situation (p.72)."

In this study family support along with the support of the Palliative Care Program were identified as being very important to the caregivers. Twelve of the caregivers (80%) in Group I reported receiving help from families. Sixty percent in Group I reported that family had come and stayed with them in order to help out during the time of illness.

The fact that family were able to come and stay was one of the main reasons the caregivers felt they were able to care for the terminally ill family member at home until death. In Group II only two of the caregivers (13.3%) reported that family were able to stay with them for periods of time while they were caring for their family member.

Lazarus (1966) suggests that when a person lacks meaningful relationships they are much more vulnerable when confronted with a possible crisis. Meaningful relationships with others provide a person with nurturance and support, resources vital for coping with a wide variety of stressors. Clemen et al. (1981) agrees that during periods of disequilibrium, persons need supportive relationships to allow them to verbalize feelings and encourage them to sort out the realities of their situation.

Patterson & McCubbin (1983) view coping as the family's ability to acquire and use the resources needed for family adaptation. These resources may be developed from within the family boundaries or they may be acquired outside the family. The quality of crisis resolution in part depends on interactions among sources of care and support within and without the family. The health care system is one of these supports.

In varying degrees health care workers are directly and indirectly involved in the family's living with a cancer experience, thus the type and quality of health care provided become important variables that affect crisis resolutions as well as the family's relationships within a network that will assist them over time in coping with cancer. If the primary caregiver is to respond constructively to the crisis of diagnosis of terminal cancer in a family member and is to develop effective coping maneuvers that serve them well during the course of caring for the terminally ill person at home, effective collaboration and coordination among facets of their entire network - including the health care system - must take place.

For many caregivers, even though they had the support of their family, they found there were times that they felt they just would not have been able to manage had it not been for the support they received from the Palliative Home Care Program.

It seemed the home care was the support many family members needed to rally around. Many felt anxious about being there alone. If you thought you were on your own it would be horrendous. Just knowing the home care was there gave you the moral support you needed.

The days there wasn't a family member here then Palliative Care would take the sixteen hours and then either my husband or I would go over and spend the night, so it worked out well.

The amount and type of service provided by the Palliative Home Care Program did not seem to be as important as the fact they were available to provide these services when they were needed or when the family felt they had reached a point where they just couldn't continue. The fact that Palliative Home Care was a professional, 24 hour service provided the support that many caregivers needed to be able to continue. One of the caregivers in Group I reported:

We just couldn't have done it, we wouldn't have known how to go about it if it hadn't been for Palliative Care and knowing there was a nurse that would come within half an hour at any time, day or night. That really made a big difference.

The findings from this study which relate to the Palliative Care team were also reflected by Wright (1987) in her study in which she reports on five indepth interviews with families selected from the Palliative Home Care Pilot Project in Saskatoon. Wright reported that throughout her interviews there were many accounts provided by the primary caregivers of the support they obtained from the various members of the palliative care giving team.

These statements overwhelmingly pointed to the value of, and the necessity for these caregivers to have such a program available to them in order to facilitate care at home. Caregivers acknowledged the value not only of the caregiving services provided to their dying family member,

but also the advice, support, reassurance and social support they received as caregivers from the palliative care team members (Wright, 1987, 157-158).

Another area of support provided by the palliative care which was reported by the caregivers as being most valuable was that the nurses came so quickly at the time of death and that they just seemed to know what to say and do. "When he died we called the nurse and she was here almost right away. She phoned the doctor. She stayed and made tea for us. They were really super."

Both groups reported the support of palliative care was important to them and had few suggestions for improvement. Most felt it was a valuable service and were impressed with the quality of worker. All caregivers were not as supportive when referring to the services provided by hospitals and physicians. There were many frustrations expressed as to the quality of care provided in both these areas.

In Group I only two (13.3%) reported that the physician had not visited in the home more than once, whereas in Group II six (40%) reported that the physician had not visited in the home more than once. Overall, the caregivers in Group I found their physician to be more

supportive than did those caregivers in Group II (5.5.4). Concerns about the care provided in hospital was an important factor in the family deciding whether care would be provided at home or in hospital (5.6.2).

Friends and neighbors were found to be helpful in certain situations but only minimal compared to the support received from family and from the Palliative Home Care Program. Several caregivers reported that as their family member became worse they preferred that only close family come to visit. At this time it seemed the support received from friends and neighbors was minimal to the client but was still found to be very supportive for the caregiver. Religion was another support system which was very helpful to some and continued to be a support after the family member's death and then there were those who felt more support from their minister and the church would have been helpful during this period of time (5.5.5).

The other community service which was mentioned as a support by five of the caregivers in Group II (33.3%) was that of the Nightingale Nurses Group. This group is an independent nursing group with a fee for service and was utilized by five families to provide night service once their family member had returned to hospital.

6.2.3 Commonalities which exist among family caregivers who are able to care for the terminally ill at home.

Caregivers differed as to specific needs, concerns, strategies and styles which they employed to manage the care of a terminally ill family member at home. Nevertheless, there were some commonalities which were identified .

Anxiety and lack of confidence were characteristics of the caregivers who were unable to care for the terminally ill family member at home until death. Other commonalities were related to age, education and health of the caregiver along with availability of support from family, friends, the Palliative Home Care Program, physicians and religion.

The findings from this study would suggest that the older the caregiver the greater the probability that the family member will return to hospital prior to death. The average age of caregivers in Group I was 54 years and in Group II was 65 years. Fourteen out of fifteen (93.3%) of the caregivers in Group II were not working outside the home. Seventy-three point two percent of all caregivers were caring for their spouse.

Other similarities suggested from the findings relate to the level of education and the health of the caregiver. Seventy-three point three percent of the caregivers in Group

I had an education of grade XII or beyond whereas 73.3% in Group II had an education of less than Grade XII. In Group I six (40%) reported their health to be good, whereas only two (13.3%) in Group II reported their health as good. Eight out of fifteen (53.3%) in Group II reported having more than one health problem. In Group I three (20%) reported having a nerve problem whereas in Group II eight (53.3%) reported having a nerve problem. The majority of caregivers (80%) reported not having any previous health care experience.

In relation to support systems, the majority of caregivers in Group I found family to be very supportive and felt that if family members had not been so willing to help out it would have been impossible to cope. "Family supports make all the difference in the world." "There is no way I could have managed without all the family support and help." There were those caregivers in Group II who found Palliative Care to be their main support. The majority of all caregivers found Palliative Care to be a valuable support.

Many of the caregivers in both groups expressed a great deal of frustration and anxiety related to the time of diagnosis. Concerns causing frustration at the time of diagnosis were related to; delay of diagnosis, delay in admission to hospital and in receiving treatments as well as the manner in which they were told about the diagnosis. There also seemed to be a general feeling by caregivers that

following the initial shock of finding out the diagnosis, they were able to reorganize their thoughts and look for ways to make the best of the time they had left to them.

The analysis of the interviews demonstrated the highly individualistic yet similar issues that caregivers were experiencing when providing care. All of the clients in Group I articulated a desire to remain at home whereas, ten in Group II (66.7%) said they preferred to remain at home and five (33.3%) were willing to return to hospital. The reasons why the client returned to hospital were discussed under decision making (5.6.2).

There was determination on the part of all the caregivers in Group I as well as some of the caregivers in Group II to be able to fulfill the wishes of their terminally ill family member to remain at home. The concept of control over decision making was very important to those caregivers providing care at home. They felt the home environment provided them with this control that they would not have had if their family member remained in hospital.

All of the caregivers in Group I were willing to have their family member remain at home to die whereas seven of the caregivers (46.7%) in Group II expressed concern about their family member dying at home. Cockburn (1983) suggested that often it is just fear of the unknown that inhibits the

family from caring for the patient in their own environment. This may be one reason for much of the anxiety expressed by caregivers in general. In this study the anxiety expressed by Group II caregivers seemed to centre around the fear of the patient dying at home.

Many of the caregivers in both groups reported receiving additional strength when it was needed to carry on. All of the caregivers in Group I were positive about their experience in caring for the terminally ill family member at home and if a similar situation arose they would not hesitate to do it the same way again.

The majority of caregivers who cared for their terminally ill relative gave generously of themselves and their love which was so needed by the dying person. No matter what the physical and mental state of the client was toward the end of their life, the caregivers were able to accept them and provided an atmosphere of caring which allowed these relatives to die with dignity. There were many caregivers who with their own physical and emotional illnesses were able to generate new energy to care for their terminally ill relative - many went nights without sleep but never complained - most felt pleased with what they were able to accomplish.

6.3 Implications for Health Care Delivery

Through a better understanding of primary caregivers and how they are able to care for their terminally ill family members at home, professional caregivers can improve and enhance care to the family as a whole. Each situation is unique and not all terminally ill persons can be adequately cared for in their home environment. The nurse must carefully assess the capabilities of the client and the caregiver along with the support systems available in order to determine if Palliative Home Care is the most appropriate form of care.

Family caregivers as well as terminally ill individuals should be provided with opportunities to participate in informed decision making about the type and the amount of assistance they wish to receive from professional caregivers. If coping strategies and support systems traditionally used by families have been effective then they should be encouraged to continue to use them whenever possible. Palliative Care services should be provided only to enhance and support existing caregiving provided by a family.

The fact that so many terminally ill persons wish to remain at home is supported in the literature review as well as by this study where 83.3% of the total group would have

preferred to remain at home until death if at all possible. Because of the wishes of the client to remain at home as well as the benefits gained by the client and family from the Palliative Care Program it would seem there is a need to increase such programs across Canada since only 10% of patients dying in Canada pass through a Palliative Care Program (Ley, 1985).

The fact that most individuals die in hospitals rather than at home as in previous generations, has denied family members the opportunity to come face to face with death. As a result of the lack of opportunity to experience death, many are unfamiliar as to how to communicate with the dying patient and how to provide support for a terminally ill patient and their family. This factor may help to explain the lack of self confidence and the anxiety about the patient dying at home which was expressed by many of the caregivers in Group II. The findings of this study would suggest a need for public education on the process of death and dying.

The findings of this study would also suggest that having more mature and better educated staff to provide respite care especially at night may add additional support to the role of the family caregiver. Overall, the Palliative Care Program in Saskatoon was well received by all the respondents.

6.4 Recommendations for further Research

1. Further research is required in the area of providing care and support for the terminally ill adult family member who wishes to die at home.

2. The results of this study would suggest the need for further research related to the level of anxiety experienced by caregivers while caring for the terminally ill family member at home.

3. Determining the knowledge of the general public in relation to the process of death and dying.

4. Further investigation in relation to the educational needs of family members involved in the care of the terminally ill patient can be conducted.

5. Another area of investigation may be related to the time of diagnosis - How can the stress level at that time be reduced?

6. Further investigation into the reasons for hospitalization of the dying patient is needed.

7. The differences between younger families and those of older families when caring for a terminally ill family member at home should be analyzed.

8. Investigation into the importance of family involvement at the time of caring for the terminally ill family member at home can be conducted.

9. A longitudinal comparison study of two groups of caregivers, those who cared for a terminally ill family member at home until death and those where the terminally ill family member returned to hospital prior to death should be done to determine how well they were able to adjust following the death of their family member.

10. Differences between male and female caregivers faced with similar situations of caring for a terminally ill family member at home should be assessed.

11. A study of the relation between the levels of education of the caregiver and patient and where the patient dies might be conducted.

In conclusion it is hoped that the experiences which were so willingly shared by caregivers of the terminally ill family members will provide information and assistance to other caregivers, families, health professionals as well as government representatives.

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APPENDIX A
PHILOSOPHY, OBJECTIVES AND
ADMISSION CRITERIA FOR THE
PALLIATIVE HOME CARE PROGRAM

HOME CARE



HOME CARE — SASKATOON
DISTRICT No. 45 INC.

Suite 500, 350-3rd Avenue North
Saskatoon, Saskatchewan S7K 6G7
Telephone (306) 934-2112

PALLIATIVE CARE PROJECT

PHILOSOPHY

The Palliative Care project is a home-based program which assists people with terminal illness to be cared for by their families. The Palliative Care Team believes that families have primary responsibility for the decisions about and care of themselves and their members. In order to enhance the well-being of the terminally ill individual and the integrity of the family, it may be their preference to have the care given at home. A coordinated intense level of support from health and social service agencies may provide the family with the help required by members to effectively care for the ill member. Where the combined resources of the individual, the family, the community, and the palliative care program cannot sustain that person at home, the suitable care in an appropriate facility is indicated.

OBJECTIVES OF THE PROGRAM

1. To ensure that the dying family member is as physically, psychologically and socially comfortable as possible through:
 - a) initial and ongoing assessment of needs;
 - b) comprehensive symptom control;
 - c) ensuring that adequate ongoing information is provided;
 - d) consultation with the person regarding care;
 - e) provision of support by the palliative care team, both ongoing and in times of acute need.

2. To maintain and improve the physical, psychological and social well-being of family members through:
 - a) ongoing assessment of family and individual needs;
 - b) ensuring that the family's informational needs are met;
 - c) consultation regarding the amount and types of care provided by family sources and the interdisciplinary team;
 - d) active involvement of the family in giving care to their dying member.

3. To inform and educate health workers and the general public about palliative care.

May, 1984

HOME CARE - SASKATOON DISTRICT #45 INC.

PALLIATIVE CARE PILOT PROJECT

Admission Criteria

1. Referrals may be initiated by anyone from the community or from health institutions.
2. The physician's referral shall establish that:
 - a) he/she consents to the referral of this person to the Palliative Care Project and either assumes responsibility for continuing involvement and symptom control or designates an alternate physician to do so;
 - b) the person has been diagnosed as having a terminal illness with life expectancy estimated to be between a week and six months;
 - c) active treatment to prolong life is no longer the goal, and the appropriate care is palliative;
 - d) the person and family are aware, or being made aware, of the diagnosis and prognosis.
3. The Palliative Home Care Coordinator shall ensure that:
 - a) the person is eligible for Home Care services under existing program criteria:
 - he/she must reside in the area served by Home Care - District #45
 - he/she has a valid Sask. Health Services card.
 - b) the person and his or her family are willing to provide an average of eight hours per day of care through personal involvement or through the private employment of caregivers;
 - c) all persons affected by the project understand that the adequacy of the provided services will be evaluated;
 - d) the cost of services to the family will be between \$30 - \$250/month.
4. All referrals shall be approved by an Admission Committee based on the stated criteria and the resources available.

It is understood that access to the additional care services will be limited throughout the term of the Palliative Care Pilot Project.

April, 1985

APPENDIX B
INTERVIEW GUIDE

Interview Guide

I understand you were able to care for (patient's name) until he/she died at home. In an attempt to better understand the role of the primary caregiver, I would like to know more about how you were able to manage to care for (patient's name) while he/she was at home.

1. Please tell me about (patient's name) and others in your family? (Probes; ages, education, occupation, and where they live).
2. Please tell me more about yourself? (Probes; age, education, occupation, employment before the illness and throughout the illness, relation to patient, physical health, religion, cultural background, living arrangements, family income).
3. Please tell me about (patient's name) illness: (Probes; the time of diagnosis, how he/she felt, how you felt; period of time between diagnosis and death).
4. I would like to know more about how you were able to provide care for (patient's name). (Probes; length of time cared for at home; Hospital admissions during this time and why).
5. What help was provided by others during the time (patient's name) was at home (Probes; formal & informal support systems e.g. health care professionals, relatives, friends & neighbors, community agencies).
6. It would be ----- months since (patient's name) passed away. As you look back, how do you feel about the care that was provided for (him/her).
7. Have you noticed any changes in your own health (physically or emotionally), either during or after this experience?
8. Had you ever been faced with a similar situation in your life? If YES - How were you able to manage at that time?
9. Please tell me more about the joys and stresses you experienced during this time? (Probes; physically and emotionally; other stressful events experienced during this time).
10. How were you able to deal with (the specific problems and stresses outlined in #9).
11. If you were faced with a similar situation in your life - what changes would you make?

12. What suggestions (recommendations) could you make for other primary caregivers who are facing a similar situation?

13. Are there suggestions you would like to make for others (including health care professionals, family and friends) who assisted you in caring for (patient's name) at home?

14. Other comments:

APPENDIX C
LETTER OF INTRODUCTION



HOME CARE — SASKATOON
DISTRICT No. 45 INC.

Suite 500, 350-3rd Avenue North
Saskatoon, Saskatchewan S7K 6G7
Telephone (306) 934-2112

1987

Dear

The Palliative Home Care Program has given its approval for a research project to be undertaken by Gail Remus, an Assistant Professor at the College of Nursing, University of Saskatchewan.

The purpose of this study is to gain a better understanding of how people care for the terminally ill at home. Enclosed is a letter from Gail Remus, which will introduce you to her and the study.

Your participation in the study is entirely voluntary. If you do not wish to be included in the study or have questions you would like to ask, please call Addie Loomis, Co-ordinator of the Palliative Home Care Program at 934-2112, or Gail Remus at 966-6253.

Thank you for taking the time to consider this request.

Sincerely,

R.P. (Phil) Gaudet
Executive Director

RPG:amp

Dear Caregiver:

My name is Gail Remus and I am presently teaching at the College of Nursing, University of Saskatchewan as well as completing my graduate work from the School of Nursing at the University of Manitoba.

I am writing to request your participation in a study related to caring for the terminally ill person at home. My interest in caring for people at home goes back several years as I have worked as a Community Health Nurse and as a Manager and Coordinator in a Home Care Program in Saskatchewan. It is my hope that this study will be of help in planning services for those people who wish to care for a terminally ill family member at home.

Your participation will involve one interview, which will be conducted by myself, and may take place in your own home at your convenience. The interview will take approximately one hour. The information you provide will be kept confidential.

Your participation in the study is strictly voluntary. I will be contacting you by telephone after (date) to answer any questions you may have. If you do not wish to be contacted or if you have any questions prior to my phone call please contact Addie Loomis, Coordinator of the Palliative Home Care Program at 934-2112 by (date) . If you would like to direct your calls to me please feel free to do so. My office number at the College of Nursing is 966-6253 and my home number is 373-1159. You may decide at any time to withdraw from the study and your wishes will be respected.

Thank you for considering my request. I am looking forward to the opportunity of talking with you.

Yours sincerely,

Gail Remus R.N., BSN.

APPENDIX D
CHECKLIST

CODE	SELF	PATIENT	OTHERS	COMMENTS
SEX				
AGE				
EDUCATION				
OCCUPATION (Pre)				
OCCUPATION (Post)				
RELATION TO PA				
PHYSICAL HEALTH				
RELIGION				
CULTURAL				
FINANCIAL LIVING ARRANGEMENTS	ADEQ INADEQ.			
	family own home & other			
DATE OF DIAGNOSIS				
TIME BETWEEN DIAGNOSIS - DEATH				
HOW YOU & PT FELT (categories)	1 2 3			
LENGTH OF TIME CARED FOR AT HOME				
HOSPITAL ADMISSIONS DURING THIS TIME	1 3			
LENGTH OF TIME OF ADMISSIONS	1 3			
FORMAL SUPPORTS	1 2 3			
INFORMAL SUPPORTS	1 2 3			
HOW DO YOU FEEL ABOUT THE CARE GIVEN	1 2 3			
CHANGES IN YOUR OWN HEALTH FACED @ A SIMILAR SITUATION	Emotional PHYSICAL YES			
HOW WERE YOU ABLE TO MANAGE @ THAT TIME	NO HOW OFTEN WHO			
JOYS & STRESSES	1 2 3			
HOW WERE YOU ABLE TO COPE @ JOYS - STRESSES	1 2 3			
DESIRED CHANGES				
RECOMMENDATIONS				
SUGGESTIONS FOR OTHERS				
COMMENTS				

APPENDIX E
CONSENT FORM

Consent Form

I -----, agree to participate in a study entitled, "Dying At Home: The experience of Family Caregivers". This study is an attempt to better understand the primary caregiver who is able to provide care for a dying family member at home.

The results of the study will be helpful to health care professionals in planning care for the terminally ill patient at home. The study is being conducted by Gail Remus who is teaching at the College of Nursing at the University of Saskatchewan as well as being a graduate student in the School of Nursing at the University of Manitoba.

My participation is voluntary and I realize that I may withdraw from the study at any time by simply telling the interviewer. If during the interview I feel I do not wish to continue, the interviewer will respect my wishes and the interview will cease. My participation or non-participation in this study will not affect the care I may need in the future.

I understand that the interview will be tape-recorded, that all tapes will be coded to ensure confidentiality and that the tapes will be erased after the study is completed. The information I provide will be reported in such a manner that no individual will be identified. The interview will take approximately one hour.

Upon completion of the study, I understand that I may request a summary of the results of the research from the researcher if I so desire. The researcher can be contacted at

I have read and understand this consent form. A copy of this form has been received by me for my own use.

Signature

Date

Witness

APPENDIX F
SAMPLE OF TRANSCRIPTS
AT THE CODING STAGE

CODED VERSION OF B:220

ID. UNR 19/10/86 220	3
#-FS # -AS	
Retired only a few days before wife's death.	4 -#
	5 -#
#-S2 # -S3	
Religion was very important-church, minister and friends were very supportive.	6 -#
	7
	8 -#
#-CP # -ES \$ -DM	
Accepting of death-ner attitude made it so much easier to care for her at home.	9 -#-S
	10 -#
!-SS	
Doctor visited at home.	11 -S
#-AH	
Joys-able to take her for drives in the fall.	12 -#
	13
\$-S1	
-the family were all present for two days prior to death	14 -S
	15 -#-S
#-AS # -FS	
Other stresses-son has a learning disability.	16 -#
	17
-son-in-law has been diagnosed with a brain tumor.	18
	19 -#
#-POST	
Since death-difficult to want to do things.	20 -#
	21
\$-CC	
-several admissions due to epigastric pain.	22 -S
	23 -#-S
#-RI	
Response to the interview-"I was really apprehensive about you coming and having to talk about this but now I am glad you came."	24 -#
	25
	26
	27 -#
#-CP # -DM	
She mentioned a long time ago-"She said, 'When I get to where I can't get around I would like to stay at home.' That was no real problem now at all because she didn't need really special care because she didn't get very sick on me-I mean as far as pain is concerned."	28 -#
	29
	30
	31
	32
	33
	34
	35 -#