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Factors Affecting Women's Caregiving Decision-Making to Accept or Decline Formal and/or Informal Support

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A thesis submitted to the Department of Sociology, Lakehead University,
in partial fulfilment of the requirements
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ABSTRACT

This thesis examines the social conditions and factors that influenced a group of women caregivers to accept or decline support in the provision of care to terminally-ill family members or relatives. I discuss the long-term impact the provision of such care may have on women caregivers' own health, and the implications this may have for more appropriate allocation of health care resources in the future. I discuss social expectations regarding the gender of caregiving, and the extent to which this group of women in Northwestern Ontario were aware of, and had access to formal and informal support, as well as the degree to which the support available was seen to be accessible and beneficial.

This research is based on both primary and secondary data collection. Primary data sources include: 1) an analysis of selective questions from a regional survey on consumer perceptions of palliative care in Northwestern Ontario; 2) tape-recorded interviews from two focus groups in Thunder Bay deriving from the consumer survey; and 3) one focus group with palliative care volunteers in the city of Thunder Bay. Secondary data sources include social science literature on gender and caregiving and a review of recent policy analyses of health care restructuring in Canada.

Similar to other studies, this research confirms gendered expectations of caregiving in chronic and long-term care situations. Assumptions and expectations held by society, family members, and women themselves reinforce the idea of women's responsibility as primary caregivers and tend to ignore the consequences this may hold for women's own health and family lives. In addition, this thesis furthers our understanding of the gendered dimension of caregiving by identifying several key factors that play a role in affecting women's decision-making to accept or decline supportive care. I argue that concerns to preserve the dignity of terminally-ill family members in institutional settings, and the desire to ensure that the patient receives quality care despite staffing shortages and limited services related to recent cutbacks in the health care system are significant influences in women's decision-making and may cause them to ignore the impact this caregiving has on their own health.

Based on the statements made by caregivers in this research, I argue that additional formal support needs to be made available and accessible to informal caregivers. Emotional and practical support would assist both the terminally-ill and their family members. Of equal importance are specific modifications to the implementation of health-care delivery to those in long-term chronic care and short-term palliative care. Presently, it is assumed that female family members are best suited to the role of primary caregivers for ill spouses, parents and relatives. Further research needs to be undertaken to examine the health consequences of this provision of care on women caregivers and to explore the context in which care is being provided. Furthermore, family caregivers have insights about patient needs that health care professionals may find instructive in contributing to the quality of life of terminally-ill patients and family caregivers. Recognition of this may alleviate women's sense of sole responsibility for the provision of quality care to their family members.

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CHAPTER ONE: INTRODUCTION

1.1 ORIENTATION OF THE STUDY

"In Canada, as in comparable Western economic systems, it is estimated that 85 to 90 percent of the care of elderly people is provided informally, largely in the context of families" (Aronson 1988:138). Studies show that in 75 percent of these families women provide the majority of care and of that, one-quarter of the caregivers are spouses, many of whom are 65 years of age or older (Himes 1994; Lueckenotte 1996). Traditionally and even today, women have been assigned the role of primary caregiver for their spouses and children (Aronson 1988). With an increase in the percentage of elderly persons in Canada, this caregiving has been extended to include primary care for a parent and/or a close relative (Lueckenotte 1996; Rosenthal, Martin, and Matthews 1996).

Caregiving refers to the financial and physical contributions provided as well as to the company and comfort extended by family members (Kahana, Beigel, and Wykle 1995:40). For many adult children, the prospect of caring for an ill parent raises concerns about how much care they should or are able to extend, and still maintain existing responsibilities and harmony within their own nuclear families (Aronson 1988). Marital and family problems can arise if time spent providing care for older relatives means that a couple's or family's time together is severely curtailed (Lueckenotte 1996:245). Factors such as being married, working full-time, and the presence of children in the home have been found to be related to a daughter's decreased ability or willingness to provide caregiving to a parent (George and Gwyther 1986; Pearlin, Mullan, Semple, and Skaff 1990; Scharlach, Sobel, and Roberts 1991 cited in Himes, Jordan and Farkas 1996). By contrast, daughters that provided short-term intensive "crisis" care for a parent indicated that geographic proximity was not a significant issue for them (Himes, Jordan, and Farakas 1996:349).

In addition to the potential development of problems between the caregiver and his, or her family, there is also the possibility of difficulties developing between the ill parent who is receiving care and the adult child providing the care. The sick parent struggles with not wanting to become a burden to their adult child(ren), and trying to maintain some control over what is happening to, or for them. Having to relinquish established parent-child roles and losing control over the ability to care for oneself while trying to maintain a sense of dignity, contributes to the receiver of care becoming frustrated or demanding in an attempt to regain some control over their lives (Schmall and Isbell 1982; cited in Lueckenotte 1996:138).

1.2 FOCUS OF THE THESIS

This thesis examines the factors that influenced a population of women in Northwestern Ontario to provide primary care for a family member, or a close friend in a palliative care setting, and the reasons that these women accepted or declined formal and/or informal support. The purpose of my research is to provide an understanding of the social conditions and factors that affect women's decision-making to accept or decline supportive care. Women's decisions are important since they may have a long-term impact on the women's own health, as well as, highlight areas in which health care resources may need to be reallocated in the future. I argue that there exist assumptions and expectations by society, family members, and even among women themselves that influence women's decision making around the care of family members. Furthermore, I argue that there are potential health risks for women who provide short-term intensive care, or long-term care in a palliative care situation which are exacerbated by social expectations about gender and caregiving.

ASSUMPTIONS AND EXPECTATIONS SURROUNDING THE ROLE OF WOMEN AS CAREGIVERS

The National Council on Aging suggests that "the experiences of women with regard to health care reflect their own attitudes, as well as those of their families, the health care professions and society in general" (1993:20). Kanana, Biegel, and Wykle assert:

> that caring and caregiving are seen as the defining characteristics of women. Watching over others involves the warm feelings and quiet domesticity persons have come to expect women to display in their customary home settings (1995:43).

Aronson's analysis of her data from interviews with thirty-two women between 45 and 85 years of age in the city of Toronto revealed that elderly mothers accepted only minimal support from their daughters as they did not want to feel obligated to them (1988). The women also commented that accepting and asking for limited assistance from daughters and friends made it easier to ask for and accept additional assistance in the future and helped maintain their sense of independence and privacy (Aronson 1988:45). A fifty-five year old daughter in Aronson's study who was the primary caregiver to her sick parent commented "I think it's our duty to do those things . . . I think most people find it natural to do it . . . you have to do certain things at certain stages of life" (Aronson 1988:50).

Studies indicate that even with anticipation of the need to provide future care for elderly family members, little prior planning is undertaken by most families. A central factor here may be the reluctance to accept the possibility of becoming dependent, or having someone become dependent on you. Those families that do make plans for future care report a higher degree of satisfaction with family discussions and planning surrounding future care provision than non-planners (Sorensen and Zarit 1996:43).

According to a divorced woman with grown children cited in Our Bodies, Ourselves (1992:283), "Women learn to accept and even expect that others will be dependent on us. Yet we fear becoming dependent ourselves " (Boston Women's Health Collective 1992). Aronson stresses that unwanted dependency on their already over-burdened daughters, as perceived by mothers, causes excessive stress to both the giver and receiver of care:

> Previously taken for granted notions of 'care' and 'dependency' are unmasked as the complex expressions of material and social relations that are strongly reinforced by ideologies concerning gender, the family, the division of public and private spheres and the role of the state. Critical analysis suggests that this pattern of care contains inherent stresses and tensions which may be expected to become more acute for women, as the majority of both caregivers and care receivers in the future (Aronson 1988:39-40).

Further, additional caring responsibilities may create significant difficulties for women as the following case study from Aronson's research demonstrates. Mrs. C spoke of feeling resentment toward her brother when she had to make the decision and arrangements to put her mother into a nursing home. The daughter expressed that as her mother's illness became worse, and her only sibling (married brother) who lived outside the city was uninvolved in the care, she came to the conclusion that she "couldn't handle everybody". Mrs C. had two young children, worked full-time outside the home, cared for her ill husband and for a time ran both her mother's and her own household. Following the death of her mother the daughter began to deal with her own failing health related to chronic health problems, heart condition, post-cancer treatment complications and impaired mobility. Because she could no longer care for her very sick husband, she had him admitted into a chronic care hospital while she remained living in the family home trying to maintain as much independence as possible (Aronson 1988 cited in Baines, Evans and Neysmith 1991:144-145). In the following quote Mrs C. expresses her thoughts and feelings on being of ill health, elderly, and in need of care:

> As my son said to me at one point: 'Mom, I'll come and help you as much as I can, but my first obligation is to my own family you know, to my wife and children'. And I thought that was callous... and then I thought afterwards: I did the same thing, you know, with my mother (Aronson 1988 cited in Baines, Evans, and Neysmith 1991:146).

Suiter and Pillemer conducted a two year longitudinal study of 57 married caregiver daughters and 1,069 members of their social network. Their findings indicate that emotional support for daughters from family members declined over the two year period, but emotional support from friends increased over time. Siblings were found to be the greatest source of both instrumental support and interpersonal stress (Suiter and Pillemer 1996:300).

Kahana, Biegel and Wykle point out that the role of the primary caregiver often involves dispensing an extensive amount of psychological, instrumental, and financial support (1995). Providing these various supports to an individual who is suffering with a life-limiting or a long-term chronic illness can contribute negatively toward the psychological and/or physical health of the care provider. Serious health problems can develop among caregivers, especially elderly caregivers. For example, the National Advisory Council on Aging asserts that there exists a potential for "developing problems such as . . . high levels of stress, high blood pressure, fatigue and exhaustion and greater susceptibility to physical illness among senior women who provide caregiving" (1993:21).

Jutras and Lavoie report from their survey of 292 households that caregivers who resided with an impaired elderly person presented with poor psychological health (1996). In addition, a study conducted by Mui which examined the health impact of caregiving on 437 spouse caregivers of frail older individuals reported the following principal findings. Wife caregivers' poor health was associated with care recipients' perceived unmet needs and increased depression, and husband caregivers' poor health status was predicted by longer caregiving duration (Mui 1996:283).

According to numerous studies (Aronson 1988;1990;The National Council on Aging 1993; Kahana, Biegel, and Wykle 1995; and Lueckenotte 1996) the likelihood of the caregiver and/or the recipient of care developing health or psychological problems is affected by the following factors:

(1) The amount of education the family and the ill person have about the illness and related issues;

(2) The type and/or severity of the illness;

(3) The amount of time the care receiver had to prepare for this responsibility;

(4) The availability of financial resources;

(5) The availability, accessibility and utilization of support systems to deal with the illness and related issues;

(6) The amounts and kinds of caregiving the caregiver will be responsible for providing;

(7) The degree of acceptance of the role and the inherent norms assigned to the role by both the provider and receiver of care; and

(8) Duration of care needed and time for socializing with others.

CAREGIVING IN A PALLIATIVE CARE SETTING

Palliative care for the purpose of the research was defined as the active and compassionate care of a person at a time when cure and prolongation of a person's life are no longer primary goals. It includes pain and symptom control, attention to physiological, family and bereavement care for the surviving family. Palliative care applies to people of any age who are in the final stages of terminal illness.

Many women provide primary supervision for spouse, parent or a relative with a terminal illness, as well as extended long-term care for a chronic illness right up until death. In a palliative care setting the primary caregiver experiences greater demands of time, psychosocial and physical support than in regular caregiving settings (Rutman and Parke 1992:24). According to Kahana, Beigel and Wykles, family practitioners often witness, following the death of a loved one, the development of symptoms, illnesses, and even fatal diseases in the individual who acted as primary caregiver to a family member (1993).

Palliative care can be perceived as a way of bringing together health care workers and volunteers to work towards the best possible care for terminally ill patients and for their families (Keizer 1992). The individual who is terminally ill may receive palliative care for weeks or even months after suffering for years with a chronic illness or, for just a few days following a massive stroke. Patients who are terminally ill from cancer or other diseases can often spend a great deal of their time moving between their home, hospital, emergency room, and outpatient clinics (Latimer 1991).

The evaluation of palliative care by families has included the examination of the quality of care provided at home and in the hospital setting since the needs of palliative care patients may be provided by family members at these various locations (Brown 1990; Davis, Reimer, and Martins 1990; Latimer 1991). Long-term illnesses can cause profound effects on both the sufferers' lives and the lives of those with whom they are in close contact. Nursing staff who provide caregiving for patients in a palliative care setting experience "higher levels of stress, exhaustion, somatic complaints, anxiety, depression, anger, and other symptoms of psychological distress than caregivers working with other types of patients" (Rutman and Parke 1992:23).

In addition, studies suggest that many nurses often leave their place of employment and continue providing care at a personal level to a parent. This additional role according to nurses contains both positive and negative aspects. The former includes a general feeling of satisfaction and an increasing sense of control of their professional lives over their private lives. The negative effects reported were those of an ethic of high expectation, the sense of being pulled in two directions, working in isolation, and being in overdrive (Ross, Rideout, and Carson 1994:43). Other consequences of providing long-term intensive care include obstructing preparations for death, increasing commitment and closeness to the dying relative, and increasing isolation of the caregiver from other associations (Kahana, Biegel, and Wykle 1995). This can lead to a more difficult adjustment for the caregiver following the death of the relative (Rosenblatt 1983; Sanders 1982; Siegel and Weinstein 1983; cited in Bass and Bowman 1990) and may increase the probability of his or her developing future health problems (National Advisory Council on Aging 1993; Miles 1991; Davis, Reimer and Martens 1990).

Kahana, Biegel, and Wykle assert that patients who are in need of life-sustaining care are aware of the non-verbal communication sent by those with whom they are in close contact with. If the provider is physically or emotionally exhausted when providing care, this can cause distress in the patient (1995). Thus, if the caring situation is unhealthy this can cause problems for both the caregiver and the patient.

GENDER AND CAREGIVING

According to many authors, conventional expectations in North America pressure women to take on the role of caregiver and provide informal and formal care to others without regard to how this will affect their own health and social networks (see for example, The Boston Women's Health Collective 1992). According to Twigg and Atkin, acting as primary caregiver in a variety of situations is not a voluntary decision for many women.

> Caring is embedded in relationships of obligation such as marriage, parenthood, [and] kinship, in which people feel responsible for spouses, children or parents, and obligated to give care. These are not voluntary relationships, and these feelings of obligation have consequences for their lives - often, as we shall see severe consequences...The element of obligation also affects how carer's interest is treated within public policy (1994:10).

Public policy differences in the kinds and amounts of services made available to female as opposed to male caregivers include women being less likely than men to receive assistance for dispensing primary care to their spouse. For example, discrepancies in the allocation of help services to male and female caregivers have been identified by Arber, Gilbert and Evandrous (1986). When single women and men requested services for their elderly parents, men received help services more often than women, and men who lived alone received more assistance with domestic and personal health services than women who lived alone.

In addition to differences in the kinds and number of services available to men and women, recent studies suggest that the current trend of women having children later in life, coupled with the present increased high rate of unemployment in Canada, may mean that adult children are more dependent on their family. This arrangement may leave many women in their fifties or sixties caring for an ill parent or relative, their spouse, and adult children, as well as contending with their own health problems that come with aging (Aronson 1988; The National Advisory Council on Aging 1993; Kahana, Biegel, and Wykle 1995). This situation is referred to as the "**dependency squeeze**". The added responsibilities of this squeeze can take an additional toll on women's overall well-being (The Boston Women's Collective 1992 cited in Our Bodies, Ourselves 1992:284).

THE EXPERIENCE OF CARING FOR A FAMILY MEMBER WHO IS TERMINALLY ILL

Terminally-ill patients and their families may go through stages such as denial, anger, bargaining, and depression before they can accept the prognosis of death (Freiberg 1987). The caregiver and family members must also contend with a" roller coaster" of feelings before their loved one dies. Their emotions are constantly changing from one day to the next. The dying person may look well one day and be very sick the next. This phase of the illness is referred to as the neutral zone. The **neutral zone**, "a place of neither moving ahead nor backward, is characterized by feelings of fear, loneliness, uncertainty, and confusion" (Davis, Reimer, and Martin 1990:19). The final stage of the illness brings apprehension of the immediacy of death. In this stage, the quality as well as the quantity of time left is a priority (Walsh and McGoldnick 1991). At the terminal stage of the disease, emphasis should be placed on the individual's physical, psychosocial, and spiritual needs (Rutman and Parke 1992; Bullinger

1992; Latimer 1991).

Families often need support to assist them in dealing with a variety of issues throughout the stages of the illness and after their loved one passes away. Instrumental, informational, practical and emotional support are some areas with which the patient and their families may need help (Loveridge and Istiloglu 1991). The needs of the patients and their families will vary in quantity and kind depending on the stage of the illness when the individual is diagnosed, during treatment and palliative care, at the funeral, and during and after bereavement (Ginsburg 1991). **Instrumental assistance** "is when an alternative caregiver takes over caregiving duties to provide respite to the primary caregiver which reinforces their self-esteem and motivation to continue providing care giving " (Kahana, Biegel and Wykle 1995:32). **Informational assistance** "provides the caregiver with information regarding available resources for the caregiver and care receiver" (Kahana, Biegel and Wykle 1995:32).

After being diagnosed the patient and his or her family may require knowledge pertaining to the illness, its prognosis, treatment, and any side-effects of treatment (Ginsburg 1991). In addition to the need for medical information, patients and their family members may want non-clinical information that would assist the family in handling the effects of the illness (Loveridge and Istiloglu 1991). Primary areas needing to be addressed include "emotional reactions to cancer; effects on work life; effects on social life; sources of information, financial effects; and services available" (Loveridge and Istiloglu 1991:43). Practical assistance may be required by the patient and the caregiver/families in the areas of shopping, transportation to treatments, and daily help at home. As the illness progresses the needs may include more support as previously mentioned, as well as an awareness of, and attention to, funeral arrangements, wills, insurance plans, work situations and financial considerations (Ginsburg 1991).

In addition to practical support, patients and families/caregivers need emotional support. Families experience considerable distress before and during bereavement (Yancy, Greger, and Coburn 1990). Common concerns expressed by individual family members include, "dealing with feelings", "accepting the presence of illness", and "feeling good about [themselves]" (Loveridge and Istiloglu 1991:44). The most difficult periods experienced by family members are when first hearing the diagnoses and after the patient's surgery (Loveridge and Istiloglu 1991). Professional mental health services are available in many larger cities to offer emotional support and answer questions from the families of patients who are terminally ill. Unfortunately these services are generally not available in rural or more isolated communities (Ginsburg 1991). Formal support is often obtained by the primary caregiver when they realize that they can no longer provide the kind and magnitude of assistance to meet the needs of their loved one (McPherson 1990). Families that experience the loss of a member often endure considerable stress (Yancy, Greger, and Coburn 1990).

Besides emotional support, social support plays a significant role in the patients and caregivers' lives. Research suggests that social support provided by health professionals to family members and friends of the patient is instrumental to the survivors' grief resolution. The optimal time for social support is during and after the patient's terminally ill phase. **Social support** "functions as a resource to facilitate people's ability to cope with the demands of their environment, thus mitigating the deleterious mental and physical affects associated with loss" (Lazarus and Folkman 1984 cited in Yancy, Greger, and Coburn 1990:25).

EXAMINING WOMEN'S CAREGIVING DECISION-MAKING IN NORTHWESTERN ONTARIO

The concerns raised above regarding the increasing expectations on women to provide caregiving for ill family members and the impact this will have on the women's own health and family lives are central to this study of women's caregiving decision-making in Northwestern Ontario. Studies have suggested that many women ask for or accept formal support when they can no longer provide the care themselves. Due to a variety of factors family caregivers receive limited amounts and kinds of support from other family members. As will be discussed later, these issues arise in my research. Trying to maintain harmony and avoiding conflict with other family members, as well as not wishing to become a burden on others, appear to be key issues among caregivers. Many women feel guilty if they are unable or reluctant to provide care for an ill family member. The wishes of ill family members often play a significant role in not only the kind and frequency of supportive care that is provided to, or for them, but also affect who dispenses that care. Furthermore, caring is not always voluntary. It is embedded in relationships of obligation--such as marriage, parenthood, and kinship--and gendered expectations of the obligation to give care. Public policy discrepancies in the allocation of services available to female, as opposed to, male caregivers were also found to affect decision-making. Finally, many women who act as primary care providers for ill family members report health risks associated with their caregiving.

1.3 METHODOLOGY

This study expands on a research project on consumer perceptions of palliative care in Northwestern Ontario conducted by Professor. M.L. Kelly, Dr. S. Sellick, B. Linkewich and S. Plumridge (1996). The earlier project was part of an Ontario Ministry of Health initiative to promote palliative care. The first phase of the consumer perceptions' of palliative care project included surveying physician, and non-physician palliative care providers in the City of Thunder Bay and Northwestern Ontario region about palliative care services. The next phase of the research was to identify the strengths and weaknesses of palliative care services in

Northwestern Ontario. A questionnaire entitled, *A Survey of Consumer Perceptions of Palliative Care in Thunder Bay and the Surrounding Region* (1996), was developed by a multidisciplinary committee of professionals and consumers to address the demographics of the population and the nature of services and care received (ie. medical, spiritual, psychosocial, home-care and other support). The rationale for this survey was to assess consumer perceptions of services or resources lacking or needed in palliative care in Northwestern Ontario. A **consumer** of palliative care was defined for the study as: a caregiver (a close relative or friend) of someone who has died in the past year who received palliative care. In addition, consumers include individuals in various stages of a terminal illness.

Building on the initial survey the Consumer Perceptions' Project conducted a second phase of research--a qualitative study using focus groups to draw out palliative care concerns in more detail. While five focus groups throughout the Northwestern Ontario region were initially planned for, only three focus groups in the communities of Fort Frances, Kenora, and Manitouwadge were eventually completed due to administrative difficulties. The focus groups conducted by the Consumer Perceptions' Project took place in the winter of 1996.

Drawing on this earlier work which focused on palliative care consumers in general, my own research is an examination of the gendered dimension of informal caregiving; in particular, the extent to which women in Northwestern Ontario were aware of and had access to formal and informal support for their caregiving and the factors which affected their decisions to accept or not to accept available support.

My research was conducted between 1995-1997 and utilized both primary and secondary data sources. Primary sources included:

(1) selective data from "A Survey of Consumer Perceptions of Palliative Care" (Kelly, Sellick, Linkewich, and Plumridge 1996), see Appendix A. Of interest to me here were survey questions that provided data on the gender of caregiving, and the implications of caregiving for caregivers' own health. This included questions 1, 4, 10, 11, 12, 13, and 14 of the consumer survey (see Appendix A). SPSS was used to analyse this data.

(2) The second source of primary data included tapes from two of the Consumer Perceptions' Project focus groups consisting of 11 participants in total. The focus groups were conducted in, and organized by, a contact in each of the rural communities. The public was made aware of the focus groups by way of posters, community television bulletin board and word of mouth. A coordinator recruited in each regional community explained the purpose of the study, and arranged a date and time in when the participanta would be available to attend a focus group meeting. The same facilitator was present at all of the focus groups and was responsible for presenting a set of questions designed by her committee that focused

on consumers' experience with palliative care. [1] An assistant, who was present at all of the focus group meetings, took note of the issues raised by group members, and ensured the operation of the audio recording of the meeting. Participants were assured that any information provided would be kept strictly confidential, and their names would not be used in the study.

During the focus groups the researcher asked open-end questions on the following themes:

1. Difficulties the consumers experienced;
2. Identification of services or resources that are lacking and needed;
3. Barriers to receiving palliative care;
4. Advice consumers might have for others who require palliative care.

I designed seven **stimulus questions** focusing on gender and caregiving (see Appendix B) for inclusion in the focus group discussions. These stimulus questions were to be administered by the facilitator during the focus group meetings. The questions dealt primarily with finding out which family members/ friends were the caregivers and, as mentioned earlier, the implications of caregiving on women's own health/stress level.

A **Focus Group** is a qualitative research method that is cost and time

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[1] Administrative problems developed during the two year study resulted in focus groups in Thunder Bay being delayed until a later date. In addition, only two focus group recordings out of the three focus groups were analysed by the author. Due to time constraints all of the stimulus questions (see Appendix B) were not consistently covered during the focus group interviews.

effective (Willms and Lange 1992). The rationale for utilizing focus group data is its ability to obtain real life experiences in a non-threatening environment. The use of focus groups has been utilised in understanding issues surrounding the delivery of health care as well as other areas. A focus group size can vary from four to twelve participants. The participants come together for a focused discussion on a common topic. The discussion is led by a moderator who asks open-ended questions. These questions are used to encourage discussion and generate qualitative data pertaining to the particular topic (Willms and Lange 1992).

As was mentioned earlier there were two sets of questions to be presented to all of the participants during the focus groups. The set of questions I designed focused on gender and caregiving. The other set of questions developed by the Consumers Project Committee focused on gathering information regarding consumers' perceptions of palliative care. My analysis of the focus group material involved looking for recurring themes that emerged from the focus group data.

(3) The third primary data source was a supplementary focus group interview I conducted with five palliative care volunteers in Thunder Bay. During analysis of the Consumer Perceptions' Project focus-group tapes I noted that due to time constraints my stimulus questions were not consistently covered. I decided that additional data pertaining to women's experiences of caregiving would be needed to help draw out the themes I wished to explore. Thus, a second phase of my research study was

initiated. The rational for conducting the informal interview was to provide an more in-depth understanding of the caregiving experience. The focus group interview was done in Thunder Bay on May 18, 1997.

I was invited by the Director of Via Vitae Community Palliative Care Volunteers to an informal gathering of the volunteers in order to present a summary of the thesis proposal and recruit participants for one ninety-minute group discussion at a time convenient to the volunteers. A time sheet provided to the group of volunteers later indicated that two individuals were interested in attending the interview. Following this, the author was presented with a list by the Director of Via Vitae of nine other palliative care volunteers who might be interested in attending the interview. From this list, three more volunteers agreed to participate. The procedures I followed are in line with the ethical guide lines set by Lakehead University. The participants who had taken part in the focus group interview were told on the phone during the first contact by the author and again later at the beginning of the interview that all information would be kept strictly confidential and of any risks. The participants were also informed that if they changed their minds they could withdraw from the study at any time. A total of five individuals participated in the interview. All of the volunteers were female and their ages ranged from 40-65. To ensure anonymity, the participants real names are not used in the thesis. The author also informed all participants that the findings from the palliative care interview would be made available to those upon request following the completion of the thesis.

The questions asked during the interview of the palliative care volunteers (see Appendix C) focused on their knowledge of the availability and utilization of formal care by caregivers in Thunder Bay. The audiotape used during this meeting was later transcribed to simplify analysis. Analysis consisted of extrapolating recurring themes from the transcribed data, and analysing them in relation to the other primary and secondary source data on women and caregiving. This type of data source was chosen because it provided information from palliative care volunteers who come into contact with caregivers. The palliative care volunteers provided information regarding availability, accessibility and utilization of supportive services by caregivers. In addition, these individuals provided insights about their interaction with caregivers, families, and other health care professionals, and about the caring situation within formal and informal settings. This focus group provided data that would have been difficult if not impossible to obtain through a survey, thus complementing the other data sources.

In addition to the primary source data discussed above, secondary data were drawn from current social science research on gender and caregiving, social assumptions and expectations regarding caregiving, and issues related to the provision of palliative care. Recent writings from the fields of sociology, social work, psychology, nursing, health policy and health care provision provide a context in which to frame my discussion of the policy implications of this research.

LIMITATIONS OF THIS STUDY

In addition to the limitation noted above regarding the inconsistent use of my stimulus questions in the Consumer Perceptions' Project focus groups, the sample of focus group respondents is too small to make generalizations to the larger population. As well, this study did not centrally address the variables of race or ethnicity, or social economic status of the focus group members and survey respondents which may have an impact on expectations of caregiving, and awareness of, and access to, resources and support programs.

SIGNIFICANCE OF THE STUDY

With the increase in the percentage of elderly women in Canada, it appears vital that formal support not only continues to be available and accessible, but that it meets the needs of the caregivers and receivers of care. Consistent with current demographic trends it is anticipated that the bulk of this burden of care will fall on women and that they will have greater difficulty securing support from formal systems for their caregiving (The National Advisory Council on Aging 1993; Baines, Evans and Neysmth 1991). It is important in the development of health care policy to understand the social conditions and factors that affect women's decisions to become primary caregivers for spouses or relatives and to accept or decline formal and/ or informal support. Where women perceive that they are "forced" to care (Baines Evans and Neysmth 1991) there may be a long-term impact on the women's own health, as well as additional areas in which health care resources may need to be re-allocated in the future

1.4 PLAN OF THESIS

Chapter Two includes a discussion of current health care delivery concerns in Canada. The main focus is policy issues that are presently affecting the allocation of health care resources, specifically those relevant to the context in which chronic and long-term care is being dispensed. This chapter includes a discussion of how analysts perceive these changes as having a significant influence on women as caregivers and providers. The areas that will be focused on include an analysis of health care delivery; health care as a form of social control; care in the community; gender based caregiving; and the privatization of health care services and nursing homes.

In Chapter Three from my analysis of the data obtained from "*'A Survey of Consumer Perceptions of Palliative Care in Thunder Bay and the Surrounding Region" (1996)*, I will discuss which family members or friends provided caregiving, to whom they provided care, and the implications of health and family problems that resulted from their provision of care. Furthermore, I discuss the kind and degree of support provided by family members, individual caregivers, and friends. This is followed by a presentation and discussion of the factors affecting caregiving decision-making that emerged from analysis of the data from the Consumer Perception Projects' focus groups. Lastly, I present and discuss the themes that emerged from my focus group interview with local palliative care volunteers.

In Chapter Four I discuss similarities and differences found among my three data sources, and how the data from my study supports and adds to the secondary source material on gender and caregiving. I note the importance to caregivers at preserving the dignity of their terminally-ill family members or close friends, and ensuring through proactive measures that ill family members received quality care. Building on this, I discuss the possible relationship between the growing awareness by female family caregivers of the cost-cutting measures many hospitals have employed (ie. cutting back on nursing staff, overworking remaining nurses, and a reduction in service provision) and women's decision-making to accept or decline supportive care. I also review the steps caregivers have taken to try to ensure that their ill family members' needs were being met in palliative care settings. Based on the findings from my research, I offer recommendations which might be helpful in future health policy development. This is followed by a brief discussion of the contributions of my research and suggestions for future research in this area.

CHAPTER TWO: THE POLICY CONTEXT OF GENDER-BASED CAREGIVING

With the growing number of elderly persons in Canada, there are more seniors requiring different kinds and amounts of caring support. And as previously noted, there exist assumptions and expectations in North America that the family, and particularly the women in the family (wives, sisters, daughters and daughters' in-laws, granddaughters, or nieces) should be responsible for caring for family members who are sick or frail, or suffering from a chronic illness (Aronson 1990). The caring situation can have a negative effect on both the receiver and provider of care (Aronson 1988, 1990; Graham 1993; Aronson and Neysmith 1997; Status of Women Canada 1998). Sheila Peace suggests that present trends in divorce, remarriage and life expectancy have complicated the caring situation. It is more difficult than ever to accurately assess health care needs and resources available for each caring situation and, with limited resources and greater demands placed on women caregivers and providers they are at greater risk to developing health problems. Changes to the demographics of the population will likely result in additional caring situations developing, such as the need to provide care for other extended family members such as step-grandparents and grandparents. There is also the possibility of seeing more widowed daughters who have outlived their spouses caring for parents (Peace 1986:67).

This chapter discusses policy issues which are currently affecting the availability and organization of health care resources as these relate to the context in which care is provided. Aronson and Neysmith (1997) argue that these changes are having a particular impact on women as caregivers and providers. I will begin by exploring recent changes made to the structure and organization of health care and social services delivery across Ontario. I will discuss how institutions and groups play a role in fostering the expectations and assumptions regarding women's caring role. This will be followed by a discussion of how changes in the availability of health care resources are pressuring women to provide long-term, unpaid care in the community.

Current health care legislation in Canada is resulting in many changes to the health care sector in Ontario. Many hospitals are undergoing restructuring, and thirty-eight hospitals across Ontario will likely be closed by the Hospital Restructuring Commission (Ontario Alternative Budget Papers 1997:100). A major factor that has affected health care delivery has been a widespread business philosophy in government combined with an urgency directed at cost-cutting (Armstrong,et al 1994:25). Researchers are reporting that many hospitals' employees are working under stressful conditions. Patients and families are concerned with the present state of hospital services and their ability to provide quality patient care (Armstrong and Armstrong 1996).

In Canada, many hospitals have seen an increase in day surgeries, with patients being sent home more quickly to recover following minor surgery or childbirth. Other changes that have taken place include the reduction and/or elimination of the number of physicians, nursing staff, aides, and cleaning staff in hospitals (Armstrong and Armstrong 1996). In addition, health care is being re-organized so that those individuals with chronic health problems are having their needs met in institutions, while individuals suffering with acute problems are being discharged quickly from expensive hospital care (Aronson and Neysmith 1997). A similar study by Armstrong et al. (1994), reveals the real consequence felt by patients resulting in part from understaffing of positions:

> Patients on the understaffed unit had a higher incidence of complications. Most frequent complications were infections, urinary tract infections, heart conditions . . . It was also identified that on the understaffed unit, patient reaches a higher acuity length of stays (LOS) than the appropriately staffed unit (1994:41).

Although many large hospitals maintain that they will ensure a commitment to 'total quality', it is important to remember that they operate from the bio-medical model based on a curative approach. This approach makes treating the whole person with care and dignity an even more difficult goal to achieve (Armstrong, Choiniere, Feldberg, and White 1994).

Many of the new policies adopted in the delivery of health care services for patients are placing added stress on hospital staff. Hospitals are now expected to focus on the number of tasks done within a given period of time. Staff are being closely regulated and less time is spent on patient's individual needs. Many patients who still need injections, monitoring, and dressings cleaned are being discharged from hospitals (Armstrong and Armstrong 1996).

With the limited availability of home care resources to meet the growing needs, the responsibility for this care falls primarily on female family members and friends, or individuals are left on their own (Aronson and Neysmith 1997; Armstrong and Armstrong 1996). In addition, researchers are increasingly finding that patients are being readmitted to hospital because their recovery has faltered in the home environment (Ontario Alternative Budget Papers 1997). Some patients have expressed concern about being discharged from the hospital when they felt that they were not well enough (Armstrong and Armstrong 1996). This costs the patient time for more treatment and it costs the hospital as well when it has to re-admit because of complications directed from early release. According to some authors these changes reflect a change in the provincial standard of patient care. (Ontario Alternative Budget Papers 1997). "Currently, due to new medical technologies and changing demographics and most importantly the cuts to hospital budgets, the hospital sector is changing its standard for patient care (Ontario Alternative Budget Papers 1997:135).

Some analysts argue that such changes in hospitals and within the health care system are a form of social control. To understand how the health care system acts as a form of social control, it is important to consider what dominant groups have power, status, and decision-making authority regarding the changes being introduced (Estes, Gerard, Zones, and Swan 1984). Administrators of institutions and leaders of corporations hold a great deal of power and influence. It is important to understand what decision-making role they play in Canada's health care system. It has been reported that individuals from the business world often head regional health institutions. Many of these people are appointed to positions of authority. "Their provincial masters tell them how much to spend and what policies and procedures to use in spending it" (Armstrong, Armstrong, Connelly 1997:8).

Aronson and Neysmith reported after careful examination of public policy and community-based care that much of the policy discourse is filled with deceptiveness regarding the representation of the many situations of elderly people in Canada (1997). What is expressed in the policy is that many of the elderly are involved in deciding the direction of long-term care. The reality is that research often does not include their experiences (Aronson and Neysmith 1997). Many seniors are in need of supportive care to deal with frailty and ill health. Aronson and Neysmith assert that seniors "can only exercise preferences or choices if real alternatives exist or can be demanded and if knowledge about them is accessible" (1997:43).

The concerns about health care in Ontario raised by these researchers are analogous to what has been presented in reports from other provinces. The report, *New Directions for a Healthy British Columbia*, (1993) states that "the provincial government sets out a commitment both to provide opportunities for good health on an equitable basis for all citizens in the province and to provide health services at home or close to home, with the support of family members and friends" (Armstrong, Choinere, Feldberg, and White 1994:95). These kinds of reports do not address the diversity of family forms that presently exist in Canada (Aronson and Neysmith 1997). Aronson and Neysmith echoed suggestions found in Graham's writings (1993) of groups to be investigated closer. . . . "people who do not have children, who do not live in heterosexual partnerships, or who do not live in western, nuclear family forms. In short, those who do not fit in with the homogeneous picture of 'family care' painted in the long-term care policy discourse" (1997:45). In essence, there are a variety of family forms that need to be recognized in the long-term care policy discourse, to ensure that their unique long-term care needs may be addressed.

In Canada, discussions on public policy and health and social services with respect to elderly persons and long-term care took place as early as the 1970s. A move for supportive care in the community and away from institutional care is underway (Aronson and Neysmith 1997). Although many elderly persons would not dispute that they would like to remain in their own homes, not all elderly persons feel the same way (Abel 1991). Abel concludes that many seniors do not want to rely on their adult child or spouse to provide often intimate, complex, and timely care. Abel conducted an involved-in-depth, open ended interview with fifty-five women (middle class and educated) who provided caregiving to a parent

(1991). Abel reported that the women had to "contend with dealing with reactivated old feelings from childhood; dealing with ongoing tension between attachment and loss; having to exert authority to which they are not accustomed; resistance to care and dealing with overwhelming demands; reviving a relationship and transforming it" (Abel 1991:112).

Tarman asserts that many adult children do not plan on when or how they will be involved in caring for elderly parents (1990). A study of caregiving daughters revealed how "physicians, social workers and gatekeepers communicated the assumption that patients' families should fend for themselves; they felt that professionals expected them to appreciate the limits of public resources but to overlook the limits of their own" (Aronson and Neysmith 1997:48). For example, in one instance a physician suggested that a woman who worked full-time, and had two children at home, should remove her frail mother from the acute care hospital. The physician told the woman that she should take care of her mother until a bed became available in a nursing home. Current health care policy shifts the care of the elderly to the family thus redistributing responsibility for care. And, as many studies indicate, the responsibility for caring primarily falls on women's shoulders (wives, daughters, daughters-in-law) rather than the shoulders of men (Aronson and Neysmith 1997).

THE PROVISION OF COMMUNITY CARE

In recent years both the federal and provincial governments have placed considerable emphasis on lowering the deficit and cost-cutting objectives and increasing efforts are being directed at embracing a model of community care. "As a matter of public policy, it is presented as an uncontroversial, sensible way of responding to elderly people's needs while also averting demographic and fiscal crisis" (Aronson and Neysmith 1997:37,38). The message constantly heard by the public is that everyone must take control and responsibility for their own health and the health of their families. These changes frequently mean greater reliance on care being provided in the community. "In theory community care essentially means that care would be provided by friends, volunteers, and neighbours within communities. In essence, it infers the "provision of help, support and protection to others by lay members of societies acting in everyday domestic and occupational settings "(Walker 1989:204).

Abel suggests that having an elderly person receive care from a family member in the home can be detrimental to the person receiving care and/or the caregiver (1991). Researchers have found that women caregivers often do not have the necessary skills and time to provide the complexity of caring needs required by a sick family member (Aronson and Neysmith 1997). Duration of caregiving in the community can range anywhere from a few days to years (Aronson and Neysmith 1997). Novak contends that older persons often face more than one chronic condition and are in need of many services (1997). Novak also stresses that accessing services can be an enormous task for those who are faced with barriers to services such as "lack of knowledge, eligibility, money, transportation, bad weather, or geography" (Novak 1997:213). Furthermore, Novak suggests that seniors who face multiple barriers, such as those who live in rural areas or who are minority group members, often have greater difficulty in accessing services. Other barriers that could contribute to minority group members experiencing difficulties in accessing services may include language, cultural sensitivity and cold winters (1997:213).

For many women there is also the reality of not having the option to obtain formal support or having family members to take on or share caring responsibilities (Chappell, Stain, and Blandford 1986). Some women have to consider reducing or quitting work to provide care for others which may result in their having to live in poverty in their retirement years (Novak 1997). Furthermore, with the exception of the Nova Scotia Home Life Support Program, programs that provide financial compensation to families that provide informal care to elderly parents are uncommon in Canada (Keefe and Fancey 1997:254).

Services to meet the specific needs of consumers are limited or not available. Furthermore, the care that is available is diminishing in quality (Armstrong and Armstrong 1996). Walker states that:

> The state occupies a dual role in relation to community care; it may provide direct support where this is absolutely necessary, but its main concern is to ensure the continuance of the prime responsibility of the family for the support and care of its own members (Bridges and Lynam 1993:39).

Care in the community is said to be less expensive than care provided in the hospital, a nursing home or a chronic care facility (Aronson and Neysmith 1997). These fiscal concerns encourage the movement of care in this direction.

PRIVATIZATION OF NURSING HOMES AND HOME CARE SERVICES

The trend towards privatization of health care services is another change which is slowly being initiated as a measure to deal with cutting the deficit (Tarman 1990). Consequently, there are fewer monies for public and non-profit extended care facilities and services, and more for-profit extended-care facilities and in home services. Beland and Shapiro's research (reviewed in Walker 1995) asserts that Canada's health care system, "highlight [s] the potential serious and far-reaching implications of the health care reforms being contemplated in Canada and, particularly, the risks they pose to older persons" (Walker 1995:38). When intervention is for home care services or nursing homes that are profit motivated the human factor can become lost (Tarman 1990). This trend is putting pressure on many women to provide care for spouse and/or elderly parents or close relatives. " In all households, the declining number of children and relatives mean fewer people are around to help with the caring load" (Armstrong and Armstrong 1996:139). The physical and mental health of both the recipients and providers of care may be in jeopardy (Armstrong and Armstrong 1996; Novak 1997; Aronson and

Neysmith 1997). Many women want to provide care for a loved one, but the demands are such that there sometimes needs to be formal intervention (Abel 1991;Novak 1997).

Many of the women who provide home care services are immigrants and may either face problems in accessing available services, or be unable to communicate to others their need for assistance with the home care they are providing (Armstrong, Choinere, Feldberg, and White 1994:100). In addition, it has been reported that these women are often reluctant to complain if they feel more services should be available. Realizing that elderly women are lonely and want to talk, these women will spend additional time providing emotional care (Tarman 1990). The accessibility of formal support is limited and not equally available to all seniors or caregivers (Armstrong and Armstrong 1996). "The shifting of responsibility to individuals also takes the form of shifting the burden of payment from all of us together through the tax system (however inequitably) to out-of-pocket costs that target individuals" (Armstrong, Armstrong, and Connelly 1997:6).

Women as primary caregivers are also faced with the difficult decision regarding placing an elderly parent into a nursing home (Aronson and Neysmith 1997). When elderly parents are admitted into nursing homes, their daughters or sisters are expected to assist in providing care. "Increasingly, women are not only expected to provide this kind of unpaid care in the home, they are also expected to provide it in institutions"

(Armstrong and Armstrong 1996:138). Studies show that even after a spouse enters an institution, the spouse in the community feels stress. "Spouses report loneliness, and a desire to get on with their lives, and feelings of guilt" (Novak 1997:342).

Privatization of nursing homes is not a new phenomenon and most provinces in Canada have supported it. Ontario has not fully supported privatization but neither has it rejected the idea.

Often family members who care for their aging or sick parent would rather not place them into nursing homes. Tarman asserts that there exist genuine concerns regarding nursing homes with respect to the quality of care, family finances, and family's feelings of guilt. In addition, family members who wish to find the owners of a privately owned nursing home to raise concerns or have questions answered often face difficulties in finding them. Tarman (1990) also questions how managers of nursing homes meet standards set by governments. Tarman points out that with limited resources and power, the local governments are left with the arduous task of ensuring that guidelines are upheld. The local governments must also ensure accountability of these nursing homes to provide responsible operation and quality care (1990).

Other concerns that have been raised by Tarman (1990) regarding private nursing homes include the following: neglect; abuse of power; heat being turned down; not having sufficient bedding and towels; staff who are untrained, unqualified and under paid; problems meeting dietary needs;

and neglect of residents who are sometimes left to sit for hours without stimulation. These are, according to Tarman, related to the decision to maximize profit (1990). While nursing homes must meet certain minimal standards, some may accomplish this task without considering the rights, dignity, and quality of care their residents receive (Aronson and Neysmith 1997).

SUMMARY

As I have described above, recent studies of health care provision in Canada indicate a growing concern regarding the allocation of health care resources, specifically those that relate to the context in which care is being provided. In addition, they show how institutions and social attitudes play a significant role in fostering the expectations and assumptions regarding women's caring role in this new policy climate.

Cost-cutting measures aimed at restructuring and re-organization of hospitals in Ontario are resulting in some patients and their families becoming concerned about the present state of hospital services and their ability to provide quality care. Additionally, the ongoing move by federal and provincial governments toward community care is shifting greater responsibility for the care of the sick and/or frail family members to well family members, usually older female family members.

These individuals often lack the skill and time to provide the often intimate and complex caring tasks required. For many women there is also the reality of not having the option to obtain formal support or having family members to take on or share caring responsibilities. Also, accessibility of formal support is limited and not equally available to all seniors or caregivers. Presently, there is limited availability of home care resources to meet the growing needs. This factor contributes to the probability that families, and primarily middle-aged and senior female family members will take on the role of primary caregiver in the home environment. Caregiving can range from a few weeks to years. Many women who provide care in a long-term chronic care or a palliative care setting are at risk of developing their own physical and/or mental health problems related to this informal care provision.

In addition to taking on the role of care providers in the home setting, families and caregivers are concerned with issues relating to the privatization of nursing homes and home care services. Care providers are expected to continue to provide some aspect of care for their frail or sick spouse and/or parent if they enter a nursing home. Placing a loved one into a nursing home is for many families and caregivers a last option. Family members and caregivers have concerns about the quality of care their sick or frail family members receive in nursing homes. Other factors that affect decision making include finances, and family's feeling of guilt. As I will be discussing in the following chapter, some of these key issues are relevant to women's decision-making to accept or decline formal or informal support.

CHAPTER THREE: RESULTS OF THE PALLIATIVE CARE CONSUMER SURVEY AND FOCUS GROUP INTERVIEWS

In this chapter I present and discuss the data that emerged from *A Survey of Consumer Perceptions of Palliative Care in Thunder Bay and the Surrounding Region* (1996), the two focus groups developed by the Consumer Survey Project Committee, and my own focus group interview with palliative care volunteers. The descriptive survey data will be presented first. This will be followed by a discussion of the primary themes that emerged from analysis of the two focus groups. Finally, I will present and discuss the primary themes that emerged after analysis of the data from the focus group interview with the palliative care volunteers.

3.1 RESULTS OF THE CONSUMER SURVEY

The following summarizes the quantitative data which resulted after an examination of selected questions from the Survey of Consumer Perceptions of Palliative Care (1996). Three hundred questionnaires were distributed. Fifty-nine of the 300 individuals initially contacted completed the survey, thus providing a context from which to understand the unique caregiving experiences from those who reside in Northwestern Ontario. For my own focus on gender and caregiving, seven relevant questions (see Appendix A. 1, 4, 10, 11, 12, 13, 14) were selected for analysis from the Consumer Survey of Palliative Care (1996). Of interest to me were those questions that asked which family members or friends provided caregiving, to whom they were providing care, and which explored possible difficulties or health problems resulting from their provision of care. In addition, I also utilized questionnaire data on the gender of the caregivers and the extent of their caring role.

In response to question one of the survey which asked the gender and age of both the respondent (ie. caregiver) and the person who had received care, the data from the survey indicated the following. More female respondents (42) than male respondents (17) filled out the questionnaire, and of those, slightly more males (31) than females (25) were reported as receiving care. The average age of the female respondents was forty-eight years of age, while the male respondents' age was fifty-six years of age. For those receiving care, the average age of the women was seventy-one (25 cases) where as the average age of the men who received care was sixty-seven (31 cases).

In response to question four of the survey which asked the relationship between the respondent and the person who received care, the data from the survey indicated the following. The relationship of the caregiver and receiver was primarily that of spouse/partner (32%), followed by that of a daughter (26%), and finally, that of son or other relative (14%).

In response to question ten of the survey which asked whether the respondent, or some other individual was the primary caregiver, the data from the survey indicated the following. Forty-three respondents indicated that they provided most of the care for their loved one (73%), and fourteen (24%), said they did not. Respondents who indicated that they did not provide most of the care, noted that it was other family members (22%) that dispended the bulk of unpaid care.

In response to question eleven of the survey which asked how much of the ongoing care respondents provided in the areas of physical, (feeding and bathing) emotional, spiritual, and practical support, (cleaning, driving, and paying bills), 45% of the caregivers (27 cases) reported that they provided ***all*** of the practical support, while 36% of the caregivers (21 cases) indicated that they provided ***most*** of the emotional support.

In response to question twelve of the survey that asked which other family members and friends were involved in providing different degrees of care, 48% of respondents reported that family helpers were ***heavily involved*** in care and 36% reported family members as ***somewhat involved*** in providing care. Forty percent of the respondents (23 cases) mentioned friends to be ***somewhat involved*** in care.

In response to question thirteen of the survey which asked how much of the person's ongoing care in the areas of physical, emotional, spiritual and practical support was provided by family and friends, respondents indicated that support by families and friends was directed primarily at providing physical support (51%), followed by emotional (48%), spiritual (48%), and finally, practical support (33%).

In response to question fourteen from the survey which asked the respondents if any problems may have developed in part from caring for the sick family member such as, personal stress for caregivers; stress in their family relationships; financial difficulties stemming from illness and/or death; problems in working out legal issues; difficulties in planning funeral arrangements; or any others, respondents reported personal stress most often (71%), followed by family stress (39%).

Part b of question fourteen of the survey asked respondents to select from the list above, which two were the most problematic. Respondents indicated that the two most problematic were personal stress (41%), and stress in family relationships (14%).

In part c of question fourteen, respondents were also asked if changes had to be made in any of the following areas of their lives to facilitate caregiving including, travel and sleeping away from home (for example, doctors appointments or treatments), requesting a leave of absence, reduced hours of work, having to quit work, relying on others to care for their ill family member, reduce leisure time, and any others. Respondents identified the majority of changes were made in the areas of travel (58%), and having to sleep away from home (10%).

SUMMARY OF CONSUMER SURVEY FINDINGS

The findings from the survey pertaining to gendered expectations of caregiving and women's experiences as caregivers support current research in this area. The data suggest that women in Northwestern Ontario are evidently taking on a significant role in caring for their spouse, parent, or relative, and these caring responsibilities may contribute to women's ill health. Also, the data shows that the women providing care made significant changes in their personal lives. The respondents indicated that most changes occurred to their travel and sleep time away from home and/or family. More time was likely needed to travel to and from doctors appointments and treatments. The added cost for travel and accommodations may be a concern for some caregivers. Problems of personal stress and family stress were mentioned as significant problems felt by many of the women who acted as caregivers.

The data suggest that many factors need to be considered to appreciate the degree to which primary caregivers and families are being affected by this additional caring role and the diverse responsibilities that come with it.

3.2 DISCUSSION OF FOCUS GROUP DATA FROM THE CONSUMER SURVEY

As previously discussed, to complement the "survey of consumer perceptions of palliative care" (1996) and allow for a more detailed examination of the factors which affect caregivers' decision-making processes regarding supportive care, two focus groups were conducted. The participants that attended the focus groups had dispensed care in the home and/or in the hospital to a family member or a close friend in a palliative care setting. Care consisted of helping with some form of physical, financial, emotional and practical support. In addition, a female primary caregiver submitted a letter to be read to focus group members in Kenora. The caregiver spoke about her experiences and thoughts on caregiving and home care (see Appendix D).

The author transcribed the recorded information from the focus group discussions verbatim. Analysis of the transcripts consisted of looking for key themes about the information that stemmed from what respondents revealed during both focus groups. After analysis of the data from both of the focus groups, the following themes emerged as significant to participants' experiences:

FOCUS GROUP THEMES

1) Caregiving in the hospital setting:

    1.1. Caregivers are emphatic that, "we know what they [patients] need and what they are feeling"- tied into monitoring patients' behaviour;

    1.2. Feeding is symbolic for another day of life;

    1.3. The nurses and institutions benefit from and accept [caregivers] our help;

    1.4. A sense of security is gained when the caregiver can realize the immediacy of support within the hospital;

    1.5. Patients and caregivers feel they are being left on their own to cope with death;

2) Caregiving reflects gendered attitudes of marital and social responsibility;

3) Caregivers are often struggling with feelings of guilt;

4) Caregivers are challenged with managing their personal lives in conjunction with the short-to-long term demands caregiving places upon them;

5) A constant frustration with diminishing formal services is evident;

6) Women caregivers appear strong and in control;

7) Home care has many limitations and potential risks;

8) Society's denial of death and dying serves to make the dynamics of the social interactions more complex;

Each of these themes will be explained in more detail below and linked to the other findings from this study.

1. CAREGIVING IN THE HOSPITAL SETTING

1.1 Caregivers are emphatic that, "we know what they [patients] need and what they are feeling"- tied into monitoring patients' behaviour

The respondents characterize themselves as being more aware than hospital staff of how their dying family members feel. For example, issues mentioned included patients not wanting to be a burden on nurses, and caregivers trying to preserve the patient's sense of privacy, dignity and pride. The caregivers suggested their loved ones used restraint when asking for, or accepting help from others, especially the nurses. For example, ringing the bell for assistance was done infrequently by the patients. However, assistance was accepted and often preferred from the female family members. Also, a few caregivers mentioned that when they noticed discrepancies in what their ill loved ones were revealing to hospital staff about the degree of pain they were experiencing, in comparison to what the caregivers observed, they would contact the patient's doctor to discuss the matter.

> **Cathy**[2]: He [son] would not ride in the wheelchair. He insisted that he was going to walk. ...he was too proud, he did not want to be a burden to anybody. . . . Even my husband in the hospital did not want to put anyone out. But, I knew he was not doing well. He would not ring the bell.
>
> **Darlene:** I was aware of what was going on, and probably the same with P and your son, and J with her husband. You know them [emphasis]. You know what they are feeling. [Speaking for group members] You look and you can see the expression on their face. You know what is going on. **[Consensus from the group]**

The comments suggest that many caregivers are monitoring and keeping mental notes of their loved one's feelings, thoughts, and behaviours while in the hospital. Caregivers refer to the knowledge they have of the sick family member and incorporate information provided by the hospital staff about the patient's behaviours and then structure their own conclusions. The preceding examples suggest that many of the caregivers believe that nurses may have difficulty detecting if some patients are experiencing pain, and, that some nurses might be assuming that patients will inform them when they need "analgesia".

> **Betty:** The nurses would come in and they would ask him how he was and if he needed any painkillers? He would say no. He did not

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[2] The names used in interview excerpts are pseudonyms to protect the anonymity of respondents.

> need anything. But, they were only down the hall and I knew he was uncomfortable and I would say "does your arm hurt"? He would say "well, a little bit." So then, I asked the doctor if he would please put on the chart that he was to be given the medication every few hours and, not to ask him, [husband] because the nurses admitted, he never rang the bell once in the months that he was here.

In addition, the caregivers provided the following explanations as to why their ill male family members reluctantly accepted assistance from others, or declined supportive care from nurses. The primary caregivers maintained that the rationale for their loved one's feelings rested on pride and trying to maintain a sense of dignity. They also did not want to be burdens to others. Also, the majority of male patients who wanted their loved ones to take care of intimate caring tasks, may have been communicating their need for a sense of privacy. On the other hand, it should be considered that healthy family members may be projecting their own need for privacy onto the patient while attempting to assume the caregiver's role and maintain their own sense of dignity. If the healthy family member were ill, they would want a family member providing primary care for them offering a degree of privacy. In the following example, the primary caregiver asserted that the patient preferred that she, rather than the nurses, carry out intimate caring responsibilities such as the manipulating of the commode.

> **Betty:** Well, even to take the commode into the washroom, I watched the very first time how they got it off and even after that I checked him

> in. He [husband] felt better when I went and did it, than for the nurses to have to.

As illustrated above, ill patients often inform their family caregivers directly or indirectly of their preference for them to carry out many caring tasks rather than having anyone else (nurses) do it for them. Daily contact for an extended period with ill people and/or having experiences to draw on provides family caregivers with additional insights.

1.2. Feeding is symbolic for another day of life

Another area of concern was that of ensuring the patient was eating regularly and properly. Caregivers noticed what and how much their loved ones ate. The caregivers stated that when they brought in foods that their loved ones liked, and/or when they ate with them, the patient's food intake increased. Occasionally, the nurses informed caregivers that the recipients of care were not eating very much and sometimes not at all. This was also often sensed by the caregiver. For family members giving the patient food, the food symbolised comfort and hope for another day of life.

> **Betty:** My husband when I was feeding him, he was never a big eater anyway, and I can remember I had taken him stewed apples because he was fond of them. . . I would say, "there are apricots on your tray, or there are stewed apples in the fridge. Which would you [husband] rather have"? He said, "both," yet he was not a big eater . . . but you are using as you say using the food . . .

> **Penny** : . . . well this is the same with us, maybe T [patient] would not have eaten if we had not been there feeding him. He also liked me with him. He would order two pieces of pie and he would say "oh that one is for you."
>
> **Amy:** I think that is the mothering in us, thinking another bite of food he is going to be here another day. **[Consensus from group members]**

A few caregivers were concerned about family members not eating if the respondents are not available to feed them. The caregivers did not complain or raise the issue regarding the patients' eating habits with nurses. Nevertheless, being there, and ensuring that the patients are eating is sending a message that they are concerned. Those family members who are unable to be there with the patient could possibly be experiencing considerable stress and feelings of guilt. For example, a caregiver alluded to the fact that her dying brother's wife was not at the hospital very often and she was.

> **Amy:** When my brother was dying . . . his wife was not there a lot of the time and I know . . . like as soon as we put something in his mouth trying to feed him the nurse would say "he will not eat".

The sister is suggesting here that if she were not there feeding her brother he would not be eating. This is quite a burden to be placed on the caregiver. These situations appear to have greatly affected the women caregivers' decision-making regarding their role in formal care provision and whether or not to rely on support provided.

1.3 The nurses and institutions benefit from and accept our help

The caregivers shared similar belief systems regarding the value placed on specific tasks to be assigned to the nurses in the hospital setting. Several of them commented that the nurses appreciated the extra assistance given by the family caregivers in that their help with the less medically important things, like making beds, gave the nurses more time to address the areas of critical value.

> **Cathy:** Well, I find the nurses were very glad of the extra help. I can make a hospital bed . . . I mean a hospital corner. I did those things, I figured they could be doing other more important things while I did those things.

The caregiver's decision to help the nurses may be influenced by the effects that cost cutting measures are having on the provision of care. The caregivers often perceive that with the cutbacks the nurses are overworked and in need of support. Indirectly, they may also be ensuring that their loved ones receive all the care they need. A consensual form of reciprocity may be occurring between the nurses and the family caregivers. The caregivers feel that with economic down-sizing and fewer nurses the resources are exhausted to a point where coping with patients' needs is a daunting task. By helping the nurses make beds, the caregivers may think the nurses will be more ready and able to meet the physical needs of their loved ones. However, as discussed in Chapter 2 what may also be occurring is that the health care system with diminishing resources is overworking the nurses and tasks are being downloaded to other family members or informal caregivers. Caregivers are intervening and performing duties that the nurses are no longer able to accomplish.

1.4. A sense of security is gained when the caregiver can realize the immediacy of support within the hospital

The women also revealed that the provision of care by the hospital staff brings them a sense of security. This feeling of security comes from knowing that their loved ones in the hospital can obtain medical services and supports that are available, reliable, and immediate.

> **Amy:** My brother-in-law passed away too, and it came to a point where you had to give so much care. I felt so much better when [Iwent] to bed at night knowing when he was in the hospital [that] if he needed immediate attention it was there for him. **[Consensus from group members]**
>
> **Amy:** Some deaths can be so difficult to carry on at home.
>
> **Darlene:** Long drawn out. **[Consensus from group members]**
>
> **Kim:** When they get real bad yes. One thing I found, he was a big man and he was kind of heavy for me, therefore, we had all those things installed so it would be easier for me to get him in and out of the shower, less struggle. . . . Then, toward the end. . . [husband went into the hospital]. Most likely, they had a wheel chair for me. [to push him in] He then went on dialysis. From then on he got more rest.

The caregivers' initial objective was to provide for the needs of their loved ones. They believed that hospitals are places equipped and staffed to provide for both medical and compassionate needs. After a period of time they became aware of the hospital's inability to address the diversity of factors associated with caregiving. Wishing to address the personal needs the caregivers were often overwhelmed in their efforts to meet the medical needs involved in caring.

1.5. Patients and caregivers feel they are being left on their own to cope with death

Another theme that emerged was that the respondents felt that physicians, nurses, and other family members ceased or decreased their attention to the dying patient over time. Many respondents asserted that over time, especially after the diagnosis, they are left on their own to give the patient comfort and support. The caregivers agreed that time just drags on.

> **Karen:** When you first get the diagnosis, it is imminent. It's urgent and you get a lot of attention. As it takes longer and longer, people stopped coming and the staff starts to ignore you when you get the diagnosis. They figure, give him pain medicine and you know, what more can we possible do?
>
> **Fran:** We are there 24 hrs a day. It would be nice if someone would come around the corner and say hello. It would be nice to see someone that comes to see them.
>
> **Sarah:** One thing that would be really nice for the people staying home is . . . I would say if the doctors would visit them even if there is nothing that they could do for them

Depending on the nature of the illness, the time that some primary caregivers dedicate to caring for family members is short, while for others providing care can last for months or even years until the patient passes away. Primary caregivers articulated this concern. Caregivers said friends and health care professionals just stopped coming after a while and this was difficult for both the patient and for them. The caregivers often feel that they are on their own. As will be discussed later, these findings are analogous with the interpretations shared by the palliative care volunteers. In essence, they are finding that some families are not visiting at all, leaving them alone without support from physicians, or other staff.

2) Caregiving reflects gendered attitudes of marital and social responsibility

Most of the caregivers said they declined offers or chose not to ask for assistance from other people. The women felt strongly that caring for your loved one is something they were obligated to and wanted to do. Family caregivers who acted as primary caregivers provided the following reasons for why they refused assistance. They asserted that they married this person "for better or worse", that the ill persons are their family members, that caregiving is a part of what is expected from spouses, and they believe that if the situation were reversed, their spouse would be there for them.

> **Amy:** I had nurses who said "well we can do that" and we said we wanted to do it.
>
> **Darlene:** You try to do it because you feel you should. It's part of when you get married. You marry for better or worse, and this is part of the

> worst part you are going to go through. You've had all these good times besides and I really like to think I would have gotten the same treatment had my partner . . . As my husband used to say "you did not expect you would ever, have to do this for your husband?" ....and, I said, "but, would you have done it for me?" He said "Yes, absolutely."

Some of these women appear to have provided care in the hospital and/or home as often as they could. Many of these women were born and raised in a generation where young women were socialized to put others' needs first. As indicated earlier, this leaves many women in positions where increasing expectations are placed on them by the health care system, society, their families, and even themselves (Aronson 1988). Many caregivers feel they must justify to themselves and others the amount and kind of care they provide for a spouse or parent (Aronson 1990).

3) Caregivers are often struggling with feelings of guilt

Most of the respondents struggled with feelings of guilt. For example, friends from church offered assistance to a woman caring for a family member. The daughter later justified her guilt feelings of not being there to help her mom, by rationalizing how a new face brought spirit back into the patient's life. Most of the respondents support the idea that the patients do get bored seeing the same face(s) all of the time. Another woman felt guilty accepting help from a friend who had gone through a similar experience. The friend offered the woman emotional support to help her deal with the pain her terminally-ill spouse was experiencing. Another woman felt comfort and appreciation when a nurse brought to her attention the extent of her ability to care for her husband at home. The nurse took the time to explain to the caregiver the limitations of caring for her very sick spouse in her home. The limitations presented to the caregiver by the nurse included not having an appropriate bed and the cost of buying one, an understanding of the extent of his illness, and the enormous amount of care he would need. The respondent still experienced feelings of guilt because she could not care for her spouse and had to place him in a home as the following narrative indicates.

> **Darlene:** I sat and talked to the nurse and told her that rather than move him [husband] into [Long-term care]. I was prepared to take him home. She [the nurse] sat down and talked to me and made me realize that I did not have the bed. That is the first thing I noticed when I put him in the hospital. I was probably hurting from all these years by bending down and pulling him up, while these young ladies . . . one, two, three and they move. It was so much different and she brought that back to me. I think though I should have brought him home, [but, I didn't] because he had very bad bleeding ulcers. I know in my heart that I could not suction them, and [I did not want to use] medication to shock [him] and bring him back. So, you do a lot of thinking about this.
>
> **Cathy:** I had a friend whose husband had died seven years previously and she was so supportive because she came over and sat with me and was able to share her experiences with me. At first when you have so much pain and he was on morphine. I found that harder to handle, how I responded to that, but, she had gone through the same thing. And. . . to me having that person who had been through this,

> well, I felt guilty because I said "I am putting you through this again."
>
> **Amy:** When I went away [on a vacation] the ladies from our church started helping mom because she was the only one at that point that could go. I think for him it was good because he saw a different face, it got really boring to have only mom and me there every day. **[Consensus from group members]** . . . [seeing someone different] brought more spirit back into him, more fight, and he could talk to somebody different. We accepted that help.
>
> **Darlene:** My situation was a little different, no matter how bad my husband was I managed to get him out every day.

These women, like so many others, want to provide some care for their ill loved one. As McPherson suggests "the degree of responsibility expressed for the support or care of an elderly parent or family member is closely related to the sense of obligation and affection built up over a period of family history" (1990:354). This tremendous load and responsibility places the family member(s) offering the care under great stress. This excessive stress may lead to potential health problems in the future.

4) Caregivers are challenged with managing their personal lives in conjunction with the short-to-long term demands caregiving places upon them

Many of these women must rearrange their schedules and make adjustments in their personal lives to be available to offer caregiving and support. They continually attempt to perform as many tasks as their ability will allow not showing in any way that caring for their loved one was a hardship or that it had affected them emotionally or physically. Many of these women made changes in their lives so they could care for their loved one. Most of them spoke of not having much of a personal life. They made changes that reflected great personal sacrifice. The following statements are from two of the women commenting on the changes in their life and the things that influenced them.

> **Darlene:** I found [my] outside life. . . Having lived on the lake my social life was not anything to write about. But, since my husband has passed away I [would] say my social life has taken off. Everybody [family] seems to think I need to eat.

Another woman cared for and stayed with her husband for seventeen years and commented that she took a few holidays.

> **Penny:** I needed to get away . . . I felt, I just had to.

5) A constant frustration with diminishing formal services is evident

While most respondents appreciated the efforts of doctors and nurses, they did have problems with the availability, and the delivery of health care services. One woman was disappointed that she did not receive the same kind of service in two different hospitals. She also was upset that no one was able to understand sign language when she needed this type of help. Most rural respondents mentioned having to make travel plans to get to the city for appointments. They did not like to having to wait so long for test results. They stayed in motels, but would have preferred it if they had family members to stay with. Ongoing expenses and cancellations of appointments were hard for patients and their families. When a new appointment was scheduled, it was usually in a few days or weeks. This left family members and patients having to reschedule their time again and pay for more expenses to travel back to the city. In essence, the caregivers were communicating their discontentment with the realization of the reduction of health care funding.

> **Sandy:** Yes, and travelling you have to travel back and forth and that's really hard on the people.
>
> **Kim:** it is a wasted trip
>
> **Fran:** . . .and if you are looking at the people that have to fly because they cannot sit for five hours you are looking at return flights and that is over three hundred dollars and that is ridiculous.
>
> **April:** I will tell you what I found when my father was dying. We went up twice and spent four days both times. But, phoning long distance and getting nothing. You know [nurse] "oh well, he is doing fine today". You liar, You go walking up there and you find he had a stroke. . . I do not find that they care in A city. When my father was dying, the nurse came in and said "would you like us to call a Minister"? "Yes, please." In this other city they never even asked us once [voice loud] if we would like our Minister there. They do not care enough. . . When my father died I was really upset. I cannot lip-read properly when I am upset because I am crying. There was no where in the city where someone could sign, so I could

> relax. . . They are going to cut some [programs]. . . . March of Dimes . . . make it one stop shopping. You can see it. You cannot say that the Home Care, Red Cross and March of Dimes are not going to start fighting for who gets the dollar. You can see it coming. It is already happening and it is going to get worse. [They say it's] good for the consumer, they will get everything in one building.

6) Women caregivers appear strong and in control

From the respondents comments about asking for, seeking out, or accepting help a contrasting common theme became evident. This theme is the importance of appearing strong and in control in the eyes of others. Most caregivers turned down offers of help from other people.

> **Amy:** I had nurses who said "well we [mother and daughter] can do that" and we said "we wanted to do it".

> **Darlene:** Yes, I think so, again I think as T said you love these individuals and [you have] your pride and dignity. . . You try to do it yourself because you feel you should.

> **Betty:** I should have some help and this is where I had sort of agreed that in the new year I may need some help, we had not got any.

The primary caregivers seem to present themselves as women who are in control of the caring situation. This representation is presented to their families, community and society. One caregiver who also works in palliative care expressed her concerns about women not accepting help until much later.

> **Sandy:** When they first start out people do not use palliative care workers. They do not realize how heavy it is going to get [another agrees]. They are snowed under before they even get to use it. You might need a half-hour or just an hour to take a breath for yourself. You might need a bit of a break.

The respondents had their own perceptions of the caring role and obtained additional information from a variety of other sources as time went on. This information consisted of both positive and negative opinions and assumptions others have about the caring role and the people who occupy this position.

7) Home care has many limitations and potential risks

As mentioned earlier a letter (see Appendix D) was submitted by a woman caregiver in the community of Kenora and read to the focus group members in that community. The woman who wrote the letter had cared for her terminally-ill spouse. Issues are raised in her letter about limitations faced by home care nurses and family caregivers. This letter in essence is a detailed account of the many struggles that a particular woman and her daughter faced when trying to meet the wishes of their dying spouse/parent.

Most of the caregivers agreed with the following issues which were raised in the letter. Caregivers have insufficient knowledge about the role of home care nurses. Primary caregivers need education and training to deliver treatments to terminally-ill family members. The demands and skills expected of primary caregivers in meeting the medical needs of their loved ones are beyond their capabilities. Hospital staff and home care professionals inform primary caregivers what practical and medical tasks individual caregivers will need to carry out the caring role at home.

Most of the caregivers said they accomplished as much as they are able to, but the limitations on individual caregivers and reluctance by some primary caregivers to perform some caring tasks needs to be taken into consideration. For example, the woman caregiver noted in her letter that she informed a home care nurse of not wanting to give subcutaneous injections to her husband. The nurse replied "if families want to keep their loved ones home to die, then, they would have to take some responsibilities. "Nurses could not be available to give subcutaneous injections on a PRN and frequent bases". In her letter the caregiver expressed the following concern: " Should a family member feel responsible for the death of the loved one because he or she gave that shot just before he died?" Most of the respondents agreed that the demands and expectations asked of them can be more than they predicted or are comfortable with.

> **Kim:** At first, I spent a few days in the hospital and they educated me for as what could be done for him [husband]. I needed home care at home for him. We had to get a special shower installed for him, what to buy, what to get for him.
>
> **Penny:** I can see some of these problems that they have indicated from my professional level.

> Home care does have some limitations on how often the nurses go in. So, when we get down to this level of care, it is not enough.
>
> **Amy:** My brother-in-law passed away too, and it came to a point where you had to give so much care.

According to Aronson and Neysmith's research, family members are required to provide some tasks if they want their loved ones to die at home (1997). One participant expressed her concern about the lack, or limited availability, of supportive services for those persons in her town who have no family members in the proximity to provide comfort and support. The caregiver noted that when those people in her town have become ill, they feel extremely isolated. The woman stated that she and others felt compelled to do something.

> **Sarah:** I think that most people know a lot of people in town and are just on their own and they feel the isolation strong. Some people have been here for ages and others have not. They are miles away from their sisters and brothers. . . And, there is nothing that you can do about that [expresses sadness]. That is a fact of life. You have to go to work. **[Consensus from group members]**. . . . or somebody, me or others feel they must be responsible and do something for the ill person.

In addition, the letter indicates that the caregiver and her family believe that the position that they were placed into was unethical. The caregivers from the focus groups commented that sometimes one can be placed in a position where one lacks training, and/or knowledge, and the level of care that is asked of you is too high. The woman in the letter raised an important issue surrounding giving injections and the possibility of this resulting in the death of the patient. She feels strongly that too high a burden is placed on people, just because both the dying individual and the family member would rather the death took place in their home. This example, and the quote below support researchers findings that present changes in the health care system are causing distress and feelings of guilt for caregivers and their families (Armstrong and Armstrong 1996). As one of the respondents noted,

> **Amy:** So, I could see in this situation where high responsibility [is expected] and then to feel guilty. Maybe we should not make the decision at a time like this.

Respondents also pointed out that they contended with internal conflicts that arose out of wanting their loved one to die at home.

> **Penny:** Yeah, but this person who is mine...says " I want to die at home," yet does the care get beyond what the caregiver can give?

8) Society's denial of death and dying serves to make the dynamics of the social interaction more complex

The next theme that emerged from the focus group discussion concentrates on the issue of many terminally-ill persons not being told directly that they are going to die by family members or physicians.

> **Fran:** And, another thing when you are talking about clients having to admit that they are dying, sometimes I find that they are not told in

> concrete ways that there are dying. They [are] maybe told," well, you have an illness, but, you got a bit of time. They are not given a time frame. "So, the doctor did not really come out and say I am dying. He said, Well, it is serious and you have a few years. Until they are told that they are dying, it is really hard to talk to these people. And maybe the wife takes you aside and tells you "well really it is worse". The family does not want to approach the subject.

Some care providers believe that before an honest communication about dying can be initiated patients have to come to terms with the prognosis. If patients are not told directly they are going to die they may not have the opportunity to address the quantity and quality of time left. A few of the participants revealed that when faced with the approaching death of a family member, they tried to conceal their pain by not accepting the prognosis. Participants agreed that holding onto a strand of hope that the patient was not going to die gave them the strength to carry on.

> **April:** I think the family holds onto the last little bit of hope. I think that is what helps you keep your sanity. I really think that is what held us together. We just did not want to believe that he was going to go. [**Consensus from group members**].

> **Fran:** But some people do not want to visit and I do not know what to say to them. I might say something that might hurt them. If they could just sit there [voice sad and frustrated] and hold their hand and be there. They don't have to say anything. If you tell people that, they just look at you.

On the other hand, families are diverse and so are their members.

They may not necessarily exhibit behaviours such as sitting and holding the patient's hand, they may avoid the patient, and avoid dealing with the impending death as much as possible.

SUMMARY OF FOCUS GROUP THEMES

As noted above there were a number of themes that came out of the focus group discussions related to caregivers' decisions to accept or decline supportive care. With regard to caregiving in the hospital setting, family care providers raised both positive and negative aspects of the delivery of care in hospitals. In particular, issues were raised by family caregivers regarding their role and the role that hospital staff play in providing care for their terminally-ill family members. Family caregivers perceive that nursing staff are overworked and this affects the kind and amount of services that nurses are able to provide. Furthermore, caregivers spoke about monitoring how much their ill family members were eating, and reported intervening when they felt their loved ones were in pain and in need of pain relief. Also of great concern to the caregivers were the feelings of isolation and loneliness felt, especially following the diagnosis. Many caregivers and their terminally-ill family members perceived that they were left on their own to cope with death. These issues are distressing for caregivers.

In contrast, hospitals are places where a sense of security is gained. Caregivers feel the immediacy of support within the hospital.

Furthermore, family care providers commented about the increasing expectations to take on more responsibilities and/or perform more complex caring tasks. For example, being expected to provide often complex and/or delicate treatments that if done incorrectly have the potential to negatively affect the well being of patients contributed to feelings of distress and guilt among the family care providers. Caregivers also spoke about feeling guilty about accepting support from others. Furthermore, assumptions and expectations held by society, family members, and the women themselves about women's roles as caregivers were key factors in why they had taken on the role of primary caregiver for their terminally-ill family member. Role expectations also explained why they limited the amount of informal (friends and family) and formal support (nurses) they accepted.

Initially many care providers limited the amount of assistance they accepted from family members or health care professionals. Many care providers truly believed that they could handle the caring situation on their own. Caregivers also felt guilty about accepting support from others. Equally important, many family caregivers perceived that the ill family member would prefer that they and not nurses provide some caring tasks, especially those that might involve concerns with privacy. As time passed, the caring situation for many caregivers became a difficult and isolating experience. In addition, those caregivers that lived in rural communities raised concerns about diminishing or lack of formal services when they needed them and stress related to the cost and time of travel.

Although faced with rational and logical reasons against providing care in the home, the emotional bond, and family and social pressure make this option a reluctant choice. They could refuse, but they will likely live with feelings of guilt and pressure from their families. Placing a loved one in the hospital or long-term care because the demands are too great rather than continuing to provide care in the home is for some family caregivers a better solution, but this decision may cause many women caregivers to feel guilty. However, as noted above, care providers asserted that they felt a sense of security knowing that in a hospital, especially, when the demands on them became so great, care is available, reliable and immediate.

3.3 THE FOCUS GROUP INTERVIEW WITH PALLIATIVE CARE VOLUNTEERS

As previously noted, to supplement the survey focus group data, an interview with palliative care volunteers was done. The questions asked of the palliative care volunteers during the interview focused on their knowledge of the availability and utilization of formal care by caregivers in Thunder Bay. Five palliative care volunteers took part in one ninety-minute informal interview. Following an introduction to the palliative care volunteers in Thunder Bay, a brief description of a palliative care client[3] will be presented. Next, the focus will be directed at presenting and

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[3] The term client(s) 'is used by the volunteers too refer to the terminally-ill persons they provide support to.

discussing the themes that emerged from the informal interview.

A local organization Via Vitae ensures that all palliative care volunteers are screened and trained. The volunteers meet frequently for support and discuss issues surrounding palliative care. The volunteers give support to terminally-ill persons and their families in the home, hospital, or long-term care institutions. The volunteers have provided support to clients anywhere from three months to three years. Each volunteer has only one client at a time. The volunteers can make referrals if their clients ask them to, or feel the situation warrants it. The Director of Via Vitae estimates that 75% percent of the clients have cancer. Approximately, 85% percent of all of the palliative care volunteers in Thunder Bay are women.[4]

THE PALLIATIVE CARE CLIENT

In response to the question addressing client's gender and marital status, and whether they lived with anyone, it was reported that most of the clients were widowed and lived alone. The next largest group were unmarried women who lived alone. The smallest group consisted of married couples with and without children. The majority of those who received palliative care lived primarily in seniors' homes. The remainder of clients lived in hospitals and in their own homes.

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[4] The Director of Via Vitae, Community Palliative Care Volunteers in Thunder Bay provided the information about palliative care and the volunteers' role.

PALLIATIVE CARE THEMES

The following themes emerged from examination of the interview material. All the volunteers that attended the focus group interview were women. This was taken under consideration during analysis as the gender of the volunteers may have influenced the volunteers' perceptions of the caring situation. Key issues discussed included:

1) False presentation of self;
2) Emotional support;
3) A perception of dissension between clients and families;
4) A diversity of caregivers;
5) Boundaries;
6) Formal services;
7) The question of equality in the distribution of services to women and men;
8) Referrals;
9) Volunteers' feeling overwhelmed;
0) Gender and the palliative care encounter

1) False presentation of self

Separating the concerns and issues put forth by volunteers regarding clients and their families is difficult as they often overlap. Most of the volunteers reported that many of their clients conceal how they feel physically and emotionally when their adult children are present. For example, clients attempted to conceal their true physical and emotional state of being in pain and their frequent experiences of loneliness and/or depression, and instead indicated that they were fine. The volunteers suggested that clients acted in this manner so as not to be burdens or to worry their families. This kind of behaviour often left both the volunteers and clients feeling frustrated following their visits with family members.

> **Tia:** I think a lot of them [clients] put on a show when their family is around.
>
> **Pam:** They do not want to be burdens.
>
> **Susan:** Yes **[others agree]**.

Also, after the family member(s) left following a visit, the clients would open up and express their true feelings and thoughts to the volunteers.

> **Tia:** You see them [clients] putting on a good front. They are happy and nothing is the matter, and as soon as they [family] are gone they [client] starts telling [you]. **[Consensus from group members]**

2) Emotional support

Many clients attempt to try to conceal extreme physical pain, feelings of loneliness, and feelings of anger from their adult children. The respondents suggested indirectly that many clients are in need of emotional support. Furthermore, clients need to come to terms with the fact that they are terminally-ill. Also, a few volunteers voiced their surprise that the client's family members are unable to see how much physical and emotional pain the clients are experiencing.

> **Susan:** They [family members] do not see what their mom and dad need that is what I am finding **(Consensus from group members).**
>
> **Susan:** I do not know why. Maybe it is the pain or they cannot accept that their other parent is sick. The one I am dealing with now she is alone in a big house and she is sick.

> The client says “Oh I wish I were in a home because I would see people. When her sister stays with her [after treatment] for a couple of days, she feels great, happy and talkative. Today, I went to see her, [the volunteer puts her head down and slouches to illustrate clients’ depressed state].
>
> **Terry:** Yes, depressed. **[Other group members agree]**

Also, it was reported by most of the participants that families have a difficult time accepting the pain and severity of the illness. They suggest that some family members may be in denial. Equally important, some families and clients often behave in ways that the volunteers are not accustomed to. A part of the volunteer’s rationale for the clients and family’s behaviours often may come from their own cultural learning. Some volunteers may lack the knowledge pertaining to the diversity of ways in which families behave.

> **Susan:**. She [client] is alone and depressed. I do not understand why the family does not see that. [speaker expresses sadness in voice]
>
> **Pam:** They do not understand, the families, they shy away, and they are afraid **[Other group members agree]** that the mother or father is seriously ill and that they are going to die.
>
> **Jenny:** They try to pretend it is [illness] not there **[All members of group agree]**

3) A perception of dissention between a client and family members

Some of the volunteers pointed out that they witnessed clients and their adult children (primarily daughters), clients and their spouses, clients and other female family members lashing out and expressing feelings of anger toward one another. These behaviours exhibited were described as strange and difficult to understand.

> **Terry:** People are strange, they get very angry and they lash out at their family and that is strange too. I guess it is human nature because you feel comfortable with your family. It is not them that you are angry at. It is the illness or something like that. If you trust them, you feel comfortable with them, you lash out at them [**Consensus from group members**].
>
> **Pam:** I had a client . . . [husband] was the main caregiver. He was very good and he worked shift work. He had home care coming in all day long. He had other services as well. She was having problems with her sisters, not responding to her. She was very angry.
>
> **Susan:** I have a client now. It is a very difficult client. The daughter lives out of town but, she is visiting her mom. There is not too much of a relationship between the mom and daughter. . . . There is lots of arguing going around. It can be hard, you know. So, she needs the two volunteers.

4) A diversity of caregivers

Most of the volunteers saw themselves, Homemakers[5], Victorian Order of Nurses, and neighbours as caregivers often filling in because families reside in another town, city, or province. They saw some daughters as already over-burdened and therefore understand why they have no time to

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[5] The term homemaker is used to refer to homecare worker. The terms homecare worker and homemaker are used interchangeably in the literature I have examined..

provide care to ill parents.

> **Susan:** Some families are not here. They are away. So, they trust people like us and VON, and, of course, neighbours. They help out. The ones I have had, neighbours are very helpful. The one I have now the son is away and the daughter is here. She has a full-time job, children, a husband and she does not have a whole lot of time. She does not have a whole lot of time to take care of her mother. ...She tries.

5) Boundaries

The volunteers also mention problems with boundaries in their roles. For example, a volunteer suggested that keeping a client company because she is feeling lonely and likely in remission is not part of her role description. There is a belief that daughters, if available, should meet this need. Many of the volunteers share similar beliefs in what should be expected of them. They agree that sometimes they perform tasks that are not what palliative care volunteers are trained for. Furthermore, they pointed out that they are often filling in where there is a real need for emotional and practical support for clients and families.

> **Terry:** The one [client] I have presently, I think the Cancer Clinic suggested she might like a visitor. . . . She seems lonely. I think she wanted company more than anything else. I do not do care for her, in that sense.
> . . . I visit and take her to appointments, things like that. Her daughters look after her as far as any care she needs. She is pretty mobile.

> **Pam:** I have a client now. She lives basically on her own. The woman has family in town.

> She does not have anyone caring for her [living with her or daily help by a family member]. She uses the services of VON, physical therapy, and friends. She has a few friends that visit her and take her places. . . Basically, there is a daughter that lives here [in town] . . . She does not come into town often. There is a son who takes her to doctors appointments and treatments.

6) Formal services

The volunteers were asked if they felt that services such as home care and nursing services are available in the community and if they felt that the client and their family members needed assistance. The volunteers felt strongly that formal services are available to meet the needs of those in the community.[6] Two volunteers pointed out that if some people in the community are not receiving services then they must not want it.

> **Tia:** Yes, it is there [formal support] if they want it **[Three out of the five volunteers agree]**

It was also suggested by the volunteers that some clients require knowledge about services, and not all of them can detect the kind and extent of services they may need. Lastly, according to the volunteers when clients are in need of a palliative care volunteer this service is not forthcoming when it should be.

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[6] I am aware of the contrasts in the comments made by the volunteers and the focus group participants regarding more knowledge and availability of health care services in Thunder Bay than the surrounding regions.

> **Tia:** A lot of them [clients], do not know it is here. [Many clients lack knowledge about the availability of services].
>
> **Susan:** They feel like they do not want help, but they need it. . . . they do not want to admit it.
>
> **Tia:** . . . And [exasperated] often they [Doctors] do not refer them [clients] to Palliative Care until there are three days left. It is really frustrating. **[Two volunteers agree]** It depends on the case.

The kinds of service referred to by volunteers for clients throughout the discussion were similar. The primary services often referred included, Homemakers, palliative care volunteers, Victorian Order of Nurses, and physical therapy. On several occasions volunteers asserted that they have felt the need to challenge their assignment when they concluded that the client does not need a palliative care volunteer. They felt the client needed someone to talk with to help alleviate feelings of loneliness.

> **Terry:** I have had cases where people have asked for a volunteer and they did not need it. They were lonely. I have one woman for quite a while. She has cancer, but it seems to be in remission. But, she has just lost her husband and the two things combined were just . . . you know. . . Well eventually, I explained to her that I didn't feel that she was in need of a palliative care volunteer and . . . because her neighbours were good to her and she had kids in town and grandchildren and friends. She was learning to drive a car and she never learned to drive. But, at this time, she was lonely, and the [H] suggested she have a palliative care volunteer. . . So, that happens occasionally and it is a very difficult situation to

> get out of. Yet, that is not what we are really supposed to be doing.

7) The question of equality in the distribution of services to women and men

Volunteers also shared their thoughts on the idea of equality in the distribution of services for their clients. Some answers that were provided by the volunteers reflected strongly held belief systems. Two volunteers stressed that men need certain kinds of assistance where as women do not. For example, men were said to need homemakers to help them with meals, and it was inferred that women did not need this kind of assistance. In contrast, another volunteer argued that maybe both male and female caregivers need homemaker services.

> **Tia:** I would think he probably needs it [homemaker]. Most men would anyway.
> **[Two group members agree]**
>
> **Jenny:** And maybe the wife needs it too. Maybe while the homemaker prepares the soup or something, she can go out for an hour or two on her own.
>
> **Jenny:** She needs it just as much as the man does [strongly voiced].
>
> **Susan:** Respite

Some volunteers began to reject the possible effectiveness of respite after hearing other volunteers draw on some experiences with it.

> **Terry:** The client's husband wanted someone to come in so he could go out for an hour or two just to get away for a while. I did that for two weeks. He phoned one day and said I do

> not think this is going to work. She does not want me to go out.
>
> **Jenny:** Yes [when doing volunteer work as a homemaker] if my client was a man, the [wife] would leave me with the client, as long as the client stayed home. Yes, I did that . . . like if he needs personal care, I do that, or cook a meal.

What is also interesting about the previous example is the consensus and shared understanding among the volunteers concerning the caregiver's arrangement for respite. Volunteers commented that sometimes their terminally-ill clients would refuse homemaker or palliative care support. The volunteers commented that the healthy spouse would cancel support services if his or her sick spouse requested it.

8) Referrals

What is also worth mentioning is the frequency with which specific kinds of services (home-care and palliative care) are alluded to and the value placed on them. Throughout the interview these above-mentioned services were given high value and referred to often. Following from this, volunteers were asked if they ever took it upon themselves to make a referral for services or intervene for clients because they were concerned about the clients well being. If they answered yes, they were asked how the caregiver responded. This question led to the participants sharing short stories of their experiences. This resulted in issues being raised regarding clients' safety, dignity, rights, and overall well being. Three volunteers stressed their high degree of dissatisfaction with the kinds of services provided for patients in hospitals and some nursing homes.

> Tia: They were not meeting clients' personal needs. [The volunteer had told a nurse that her client had to go to the washroom]. The nurse replies "the patient went half hour ago. She will be ok she has a pad on." The volunteer replies by saying " that makes me more upset than anything." That is just what they [nurses] say [**Consensus from group members**].

> Tia: It is such a sad thing. [The group expresses feelings of helplessness in these situations].

> Tia: So I said to him [husband who was caring for his wife] you really have to look after yourself because you are going to end up in the hospital. . . He said, A few years ago, I had a serious operation and she looked after me. She did not put me into any home.

9) Volunteers' feeling overwhelmed

It was mentioned frequently throughout the case examples how volunteers have felt the need to go beyond their role specifications. This sometimes contributed to volunteers' feeling frustrated, angry, and helpless. Lastly, most of the volunteers felt that many of their clients families place them in positions of trust because they live in another town, city, or province. Three volunteers reported that they have frequently intervened on their client's behalf. A palliative care volunteer expressed her disappointment with the manner in which nursing staff treated a client and thus, requested the nurses make some changes.

> **Jenny:** I raised hell at this one place. I had a patient there. . . . This woman was dying. [Voice loud and stressed the word dying]. They [the nurses] sat her (client) up in a chair and tied her down. And [voice angry and then sad] they sat her in the lunch room. I said to them [nurses] "how long has she been sitting there"? It was 2:pm when I visited her. The nurse said "from eleven." [The room was silent]. I said "get her out of there and put her to bed right away." "You know . . . she is dying. What are you doing [surprised at clients' state]" She died not long after that. I was really upset.
>
> **Susan:** Some families are not here they are away [live out of town]. So they trust people like us, Victorian Order of Nurses, and neighbours [**Consensus from the group**]

Families may encounter similar situations as the palliative care volunteers in hospitals and nursing homes as well, and feel just as angry and frustrated. Caregivers/families faced with situations where they feel they have no power over what is being done to, or for their loved ones, might experience feelings of helplessness.

Finally, this last story is about a male patient who, according to the volunteer, was in a great deal of physical pain and often kept his feelings to himself. The hospital staff appeared to be unaware of how much pain the client was experiencing. Nurses commented that occasionally they would hear the client let out a scream. The volunteer commented that the patient never screamed in her presence. According to the volunteer, she knew the patient was in pain, but he was reluctant to ask for medication. This kind of situation can put a great deal of pressure on family members.

They may feel they must monitor specific situations to ensure that others in positions of responsibility are meeting the patient's needs.

> **Tia:** He [client had a stroke and has arthritis] is really in so much pain. When I go in to see him, the first thing I do is give him some apple juice. I think he just wants that and then for me to leave. . . .The staff does not think he is in pain. They say that occasionally he will let out a scream. When I am there, he does not do that. I felt that he just did not want me there. After that I kept him company and got to know him a little better.

10) Gender and the palliative care encounter

The volunteers reported that the manner in which clients and volunteers communicate with each other is affected by the gender of both individuals. Four of the volunteers suggesting that clients would feel more comfortable talking and expressing their feelings with someone who is of the same gender.

> **Tia:** Clients sometimes need someone who can speak their language.
>
> **Terry:** There are not enough male palliative care volunteers and that is a problem. If I were in the same situation, I would want a woman visiting me. I would not want a man visiting me. **[Consensus from group members]**
>
> **Terry:** I am sure that a man would want a man [palliative care volunteer]. **[Consensus from group members)**

The comments provided suggest that the volunteers believe that female and male clients would prefer volunteers of the same sex. The volunteers are also sharing their own opinions on whom they would be more comfortable with and who they could possibly relate to better.

SUMMARY OF PALLIATIVE CARE THEMES

The palliative care volunteers noted that some of their clients had family members who did not reside in the city. All the volunteers were female. The gender of the volunteers may have played a significant role in their perception of the primary caregiver's role. The volunteers saw themselves, neighbours, and homecare service providers as the caregivers. Furthermore, they commented that daughters of the clients who are married, have children and work full-time are often unable to take on additional caring responsibilities. Volunteers also commented that sometimes they have had to go beyond what is expected from them in their role. They have sometimes intervened on the client's behalf. The palliative care volunteers noted that their clients are primarily made up of widows who live in hospitals, nursing homes, or their own homes. Many of the ill persons and their family members appear to be in need of emotional, practical and informational assistance. Volunteers reported that many of the terminally-ill persons they come into contact with appear to suffer from depression and loneliness. A specific family member providing caregiving was not frequently seen at the hospital, nursing home, or the client's own home. But, when there was a family member present providing care, it was primarily a female relative or spouse.

SUMMARY OF THE CHAPTER

In this chapter I have presented and discussed the data that emerged from the consumer palliative care survey and the focus group interviews. From my analysis of the data obtained from *"A Survey of Consumer Perceptions of Palliative Care in Thunder Bay and the Surrounding Region" (1996)*, it was determined that female family members or friends provided the bulk of caregiving, and that personal stress and stress in family relationships also resulted from this provision of care. Findings from the consumer survey were followed by a presentation and discussion of the factors affecting caregiving decision-making that emerged from analysis of the focus group data that derived from the earlier palliative care survey.

One of the themes that emerged in my analysis was concerns about the quality of caregiving in the hospital setting, specifically, family caregivers efforts at preserving the dignity of their terminally-ill family members, as well as ensuring the patient received quality care despite staffing shortages and limited services related to recent cutbacks in the health care system. For example, caregivers spoke about monitoring if and how much their ill family members ate, and reported intervening when they felt their ill family member was in need of pain relief. However, assistance was accepted and often preferred from female family members.

The next theme that emerged reflected gendered attitudes of marital and social responsibility. The women caregivers felt strongly that caring for your loved one is something they were obligated to and wanted to do. Most of the caregivers said they declined offers of support or chose not to ask for assistance from nurses or family members. Also, of considerable concern to caregivers and recipients were the feelings of isolation and loneliness, especially following diagnoses. Some caregivers and their terminally-ill family members would have appreciated having the physician or nurses visiting them more frequently. Caregivers also spoke of often struggling with feelings of guilt about being a burden to others. Caregivers were challenged with managing their personal lives in conjunction with the short-to long-term demands caregiving places on them. Many of the caregivers rearranged their schedules and made adjustments in their personal lives so they would be available to offer caregiving and support. It was important to these women not to appear in any way that caring for their loved one was a hardship, or that it had affected them emotionally or physically. In addition, family care providers were constantly frustrated with diminishing formal service.

Although the caregivers appreciate the efforts of doctors and nurses, many experienced problems with the availability, and delivery of health care services. For example, most rural respondents reported stress related to travelling to (cost and travel time) the city for treatments or doctor appointments, as well as locating suitable accommodations (close to hospital and not expensive). Caregivers appeared to want to be strong and in control in the eyes of others. For example, some caregivers turned down early offerings of informal and formal support, or did not seek out support. Moreover, participants did not realize the caring situation would become so demanding or unmanageable.

Another theme that emerged from analysis included concerns about home care. Caregivers spoke about the limitations and potential risks they saw in home care. For example, caregivers raised concerns around increasing expectations placed on caregivers. One particular caregiver spoke about a situation where she was expected to provide caring tasks that if done incorrectly had the potential to cause harm to the terminally-ill family member. These kinds of situations contributed to feelings of distress and guilt among the family care providers. Family members who are unwilling or able to act as caregivers, or who are reluctant to perform specific caring tasks need to have health care professionals respect their decisions. Caregivers also expressed a sense of security knowing that in a hospital, especially, when the demands on them become so great, care is available, reliable and immediate.

Finally, I presented and discussed the issues that emerged from my focus group interview with local palliative care volunteers. Many clients concealed their physical pain and frequent experiences of loneliness/and or depression from their adult children. Formal intervention (emotional and practical support) for the clients and their family members may be helpful. The palliative care volunteers whose clients are primarily older widows saw family members as playing a limited role in providing care to their clients. The female volunteers saw themselves, neighbours, nurses, and homecare workers as caregivers. The volunteers observed that many of their client's adult children and relatives live out of town. Also, volunteers mentioned problems with boundaries in their roles. They commented that sometimes they have provided emotional and practical support to their clients. This left some volunteers feeling overwhelmed. This would suggest that attention needs to be directed at respecting the boundaries and limitations of the volunteers' role and ensuring that appropriate support is provided to clients and their families.

CHAPTER FOUR: CONCLUSION

In this chapter I have examined the social conditions and factors that influenced women caregivers in Northwestern Ontario to accept or decline support in the provision of care to terminally-ill family members or relatives. I have argued that key factors affecting women's decisions to accept or decline supportive care are their perceptions of the availability and quality of existing care, concerns about the dignity and privacy of the patient in institutional settings, and gender expectations of social and family obligations to provide care to family members. After a brief discussion of similarities and differences in findings from my three data sources, and a discussion of how my findings relate to the secondary source material reviewed, I offer some recommendations for health care delivery and suggestions for future research based on this data..

SIMILARITIES AND DIFFERENCES FOUND AMONG THE THREE DATA SOURCES

Similarities were found among the data from the two focus groups and the interview with the palliative care volunteers. The female family caregivers, the palliative care volunteers, and the terminally-ill family members experienced feelings of isolation and loneliness following the diagnosis. The caregivers, volunteers and patients would have preferred ongoing contact from doctors and nurses, especially, when other family members and friends stopped visiting.

Furthermore, the gender of the caregivers or providers in all the data sources were primarily female. The palliative care volunteers whose clients are primarily older widows saw family members as playing a limited role in providing caregiving to their clients. The female volunteers saw themselves, neighbours, nurses, and homecare workers as primary caregivers. The volunteers observed that many of their client's adult children and relatives live out of town. When there were family members providing care they consisted primarily of females. Similar findings were reported in the two focus groups. Some of the caregivers commented that they feel many elderly persons who live in small towns in Northern Ontario who are in need of supportive care have no family members living in town to provide informal care.

Also, the data from the palliative care survey and the focus group interviews show similar findings with regard to caregivers experiencing health or stress problems, as well as stress in family relationships while they were responsible for the provision of care to terminal-ill family members or friend.

Some differences were also found between the data sources. Palliative care volunteers wanted physicians and family members to inform the client directly that they were going to die, whereas, some caregivers from the two focus groups mentioned that they were in denial and found comfort in believing that the patient was not going to die. Furthermore, some focus group participants expressed anger and frustration with the health care system's inability to meet their needs. However it was unclear as to whether they voiced their complaints to health care professionals. As the focus group interview with the volunteers revealed, it was primarily the volunteers that made suggestions to health care professionals about patient care. The volunteers also became angry when they observed that the clients dignity needs were not being met.

MY DATA WHICH SUPPORTS SECONDARY SOURCE MATERIAL

My data supports secondary source material on the issues of gender and caregiving. For example, assumptions and expectations held by society, family members, and women themselves reinforce the idea of women's responsibility as primary caregivers and tend to ignore the consequences this may hold for women's own health and their family's lives.

In particular, all of the female family members wanted to be involved in the provision of some aspect of care for their loved ones. Similar findings were noted earlier in Aronson's (1988) research showing that women caregivers feel strongly that caring for a loved one is something they are obligated to and want to do. Research cited earlier by Aronson and Neysmith (1997) also spoke about caregivers experiencing feelings of guilt when they placed their spouses into long-term care. Most of the women in the study expressed some concern about the levels of care that were asked of them.

Armstrong and Armstrong (1996) expressed similar findings in their research. Women caregivers are increasingly being expected to provide intimate and often complex treatments (ex. giving subcutaneous injections to their loved one) that they not only feel is beyond their capabilities, but if done incorrectly, could result in physical harm to the patient. Similar to what was mentioned earlier in Novak's writings (1997), women caregivers and providers commented that they provided caregiving that was beyond what they had expected. The women participants in the Consumer Perceptions Survey were heavily involved in the provision of care. Novak also pointed out that many women caregivers wait until the caring situation is more than they can manage before asking for or accepting help (1997).

As noted earlier in Arber, Gilbert, and Evandrous' research (1986) public policy differences were found in the kinds and amounts of services made available to female as opposed to male caregivers. In particular, caregivers expressed frustration with diminishing formal services, especially, with regards to finances and time needed to allocate for travel and accommodation to treatment centres. Lueckenottes' writings (1988) as noted earlier raised concerns found in the data about caregivers and providers efforts to maintain harmony and avoiding conflict with other family members. Aronson (1988) also spoke about women caregivers having to struggle with feelings of guilt when they were unable to meet the responsibilities placed on them.

DATA WHICH FURTHER DEVELOPS SECONDARY SOURCE MATERIAL

This research furthers existing data on gender and caregiving by detailing specific factors which affect caregiving and caregiving decision-making. For many caregivers preserving the dignity of their terminally-ill family members or close friends, and ensuring through proactive measures that ill family members received quality care in palliative care settings are important considerations. Many of the caregivers and providers monitored if, and how much, their ill family member or friend was eating and/or if they required medicine for pain relief. Many caregivers and volunteers took it upon themselves to ensure that the dignity of their loved one or friend was protected and their need for privacy was met. The primary caregivers maintained that the rationale for their loved one's feelings rested on pride and trying to maintain a sense of dignity. A recurrent theme was expressed that the clients did not want to be burdens to others. Moreover, the majority of male patients who wanted their loved ones to take care of intimate caring tasks, may have been communicating their need for a sense of privacy.

Similar findings were reported by the palliative care volunteers. The volunteers exhibited feelings of helplessness, frustration, and anger when they spoke about the times they had found themselves taking responsibility for preserving the dignity of their clients. For example, some of the volunteers commented that they had observed a few clients not being treated with dignity by the nurses in the hospital. The volunteers, like the caregivers, as will be discussed below, may be observing the consequences brought on by the reduction of health care funding and cutbacks on staff.

I believe the growing awareness by female family caregivers regarding the cost-cutting measures many hospitals have employed directly impacts on their decision-making regarding accepting or declining supportive care. This would directly correlate with a sense of personal responsibility in ensuring that family members needs were being met in palliative care settings.

For example, the family caregiver's decision to help the nurses may have been influenced by the effects that cost-cutting measures are having on the provision of care. Initially, many of the family caregivers took it upon themselves to help with some aspect of care provision for their terminally-ill family member or friend while they were staying in the hospital. Caregivers commented that they observed that the nurses were overworked. A few caregivers' perceived that by helping the nurses make beds, the nurses may then be more ready and able to meet the physical needs of their loved ones. Concerns to preserve the dignity of terminally-ill family members in palliative care settings, and the desire to ensure through proactive measures that the patient receives quality care despite staffing shortages and limited services are significant influences in women's decision-making and may cause them to ignore the impact this caregiving has on their own health.

4.1 RECOMMENDATIONS

Based on the findings of this study the following are some recommendations which might be helpful to address the concerns raised by women caregivers in the development of future health policy.

- Every effort should be made by those that work in palliative care settings to ensure that the quality of care, as well as the patient's dignity and privacy needs are preserved.
- Many caregivers and recipients may benefit emotionally from periodic communication with the recipient's physician and a social worker. This may facilitate in alleviating the family caregiver or provider and recipient's feelings of isolation and loneliness. In addition, this would be an appropriate time to exchange information about the caring situation and assess if problems exist regarding personal stress or stress in family relationships.
- Many of the women caregivers found it extremely difficult to be relied upon extensively when their loved one was in need of a high level of care . Intervention in the form of guidance, education information, and formal support may be helpful to caregivers if it is provided gradually, and in such a fashion where the caregiver feels that she is still in control of the caring situation. It is important to do this before the situation reaches a crises, as it may be difficult to

intervene at this stage.

- For some families it may be helpful to arrange for the recipient's physician, a manager of patient and family care, family member(s) and recipient to meet and work together to create a flexible caring plan. This alleviates any one individual from assuming or being presumed to take sole responsibility as the role of caregiver is not always voluntary. Furthermore, women who refuse or are unwilling to act as caregivers should be supported in their decision.
- An understanding by policy makers of the social conditions and factors that affect women's decision-making to accept or decline supportive care may reduce the possibility that the responsibility of caregiving falls solely on women's shoulders. Family members, health care providers, society, politicians, and corporate leaders must share in the responsibility of caring for the growing numbers of seniors that will be in need of health care resources.
- A certain amount of flexibility needs to exist in the system to ensure that the voices of family caregivers, providers and the recipient's are heard. This is imperative regarding the assignment or discontinuance of health care providers, social service workers, or home care workers. Information about choices and options in the area of formal support need to be available, accessible and understandable, so seniors and caregivers can make informed decisions. When caregivers and recipients wish to act as their own

agents in planning and selecting professional and paraprofessional services to facilitate their goals systems need to be both enabling and supportive.

- Government should coordinate its efforts with palliative care agencies, personnel, family members, and patients to secure the necessary supportive services to ensure the patient has the option to remain in the community.
- Equity in the availability, access, and distribution of health care resources needs to be considered to address the gender gap in current services. In addition, supportive services should be coordinated, comprehensive, and consistent in efforts to achieve effectiveness and efficiency.
- Recipients who want to remain in the community, but do not have family members available, willing, or able to provide informal caregiving, should not be penalized. Health care policy planners need to consider individual and family differences and try to develop ways to provide adequate care for these individuals, such as attendant care.

Community care is increasingly becoming a reality. Diminishing health care and social service resources are unprepared to meet the growing demands occurring from an aging population. With all levels of government initiating cost-cutting measures, the shift towards community care will continue. Prevalent social attitudes lend themselves to an axiom whereby this service will be delivered primarily by women. The potential long-term cost could be considerable in terms of health, stress, and financial problems for these women.

4.2 CONCLUSION AND DIRECTION FOR FUTURE RESEARCH

This research contributes to the field of sociology and expands on existing data on gender and caregiving by detailing specific factors which affect caregiving and caregivers' decision-making. Many of the caregivers experienced stress and a decrease in their social life as a result of caregiving. Similar to other studies, this research confirms gendered expectations of caregiving in chronic and long-term care situations. For example, we are witness to the anxiety and guilt of caregivers largely because of the assumptions and expectation held by society, family members and even the women themselves which reinforce the idea that women are best suited for the role of primary caregiver. Formal support needs to be available and accessible to informal caregivers and other family members also need to be considered as potential caregivers.

It is hoped that this research may assist those professionals who develop policy regarding the distribution of health care resources. The information may provide them with an understanding of how terminally-ill persons and their families/caregivers are presently being affected by the cutbacks. The majority of caregiving is carried out by women, and the expectations and demands placed on them are likely to continue to increase. This study may be of interest to individuals, families, seniors' groups and organizations for the purpose of educating and policy implications.

FUTURE RESEARCH

The majority of caregiving is carried out by women, and the expectations and demands placed on them are continuing to increase. My research highlights the need for future research to examine the potential health consequences of this provision of care on women caregivers. Future research might include monitoring the health status of women during their time of caregiving and after their ill family member has died. This may provide us with evidence of the specific health outcomes of women's caregiving. To explore the context in which care is being provided future research might include examing additional factors not included in this study which may affect women caregiver's decision-making to accept or decline supportive assistance. For example, location, race or ethnicity, and social economic status may have an impact on expectations of caregiving, and awareness of and access to resources and support programs.

APPENDIX A

SELECTED QUESTIONS FROM *THE SURVEY OF CONSUMER PERCEPTIONS OF PALLIATIVE CARE IN THUNDER BAY AND THE SURROUNDING REGION (1996)*.

Questions 1, 4, 10, 11, 12, 13, 14) were used from the survey.

1.A. your gender: male or female
B. person's gender: male or female
C. your age ___
D. person's age ___

4. What best describes your relationship to the person?
Spouse or significant other_sister_ brother_daughter_son_
other relative:relationship_friend_

10. Did you provide most of the care for the person? (Not including paid care)

yes_ no_

If no, who provided most of the non-paid care for the person?__ (state the relationship and indicate gender)_____

11. How much of the person's ongoing care did you provide in each of the following four areas? None Some Most All

A. Physical care (feeding, bathing etc).
B. Emotional support
C. Spiritual support
D. Practical support (cleaning,driving,paying bills etc.)

12. Besides yourself, who else of the person's relatives and friends was involved in the person's ongoing care? (Check all that apply)

	Somewhat involved In care	Heavily involved in care
Family: How many members?	_____	_____
Friends:How many?	____	_____
No one		

13. How much of the person's ongoing care did family and friends (identified in question 11) provide in each of the following four areas?

	All	None	Some	Most
A. Physical care (feeding, bathing etc.)				
B. Emotional support				
C. Spiritual support				
D. Practical help (cleaning, driving, paying bills etc.)				

14. In your opinion, caring for the person resulted in: (check all that apply)

__personal stress for the caregivers
__stress in family relationships
__difficult financial costs related to illness and death
__problems in working out legal issues, ie., power of attorney, etc.
__difficulties in funeral planning
__other

B. Of the above, which two were the most problematic?

C. The person who provided most of the unpaid care had to:
(Check all that apply)

__travel from home
__sleep away from home and/or family
__arrange leave of absence from work
__reduce hours at work
__quit work
__rely on others to care for their own family (spouse, child, friend)
__reduce leisure time
__other

APPENDIX B

ADDITIONAL STIMULUS QUESTIONS ADMINISTERED TO FOCUS GROUP PARTICIPANTS

1. If it was predominantly your responsibility rather than any other member of your family to provide the care, what factors influenced this decision?

2. If you considered or declined assistance or additional assistance from family members or formal agencies what affected your choice?

3. If you were aware that practical or emotional support was available in your community would you have second thoughts about using it?

4. At any time did family members directly or indirectly influence your choice on becoming the primary caregiver ?

5. Taking into consideration your gender, do you think it played a part in how society, family members, and/or you perceived who should provide the care?

6. When you distributed your time and energy with the responsibility of caring for your own family and that of caring for your sick family member or friend what adjustments or changes did you feel had to be made by you, and why?

APPENDIX C

QUESTIONS DESIGNED FOR THE PALLIATIVE CARE VOLUNTEERS

1. Why did you become a palliative care volunteer?

2. In your experience, are caregivers primarily male or female?
Why is this?

3. As a volunteer, were there situations when the primary caregiver appeared to be responsible for many things? What were they responsible for ? Did they get assistance from family, friends or help service with these things.? Drawing from your experiences and knowledge why do some women caregivers have help while others do not?

4. For those women caregivers that refused help, do you think their relationship with the patient (husband, father, or mother) may have influenced their decision to accept or decline assistance? Why do you think this is so?

5. Would you consider the availability, accessibility and utilization of health care services equal for male and female caregivers.?

6. Could you give us your perception of the primary caregiver's role? Do you think this is the same for men and women? Do you find that the patient and other family members, as well as helping professionals in general, share this belief ?

7. Did you ever make suggestions to caregivers or make referrals for support because you were worried about them and/or the patient's well being? If yes, how did the caregiver respond? Were you met with resistance when you mentioned your concerns?

8. When you first meet the patient and his/her family, how do they respond to you as a palliative care provider? Why do you think they respond to you in this way? As time passes, does this behaviour stay the same or change?

9. Considering the gender of the patient /caregiver did you sometimes find yourself or others adjusting what was said and done for these individuals?

10. What do you think are the biggest challenges palliative care volunteers must work through in order to accomplish their goals?

APPENDIX D

LETTER A- A CAREGIVER SPEAKS CANDIDLY ABOUT HER ENCOUNTERS WITH THE HEALTH CARE SYSTEM AND THOSE IN THE HEALTH CARE FIELD AS SHE ATTEMPTED TO MEET THE WISHES OF HER TERMINALLY ILL HUSBAND.

This letter was submitted by a female caregiver in the community of Kenora and it was read during the focus group meeting. The letter is about a woman who cared for her terminally ill husband in their home. The letter speaks about caregiving and home care.

> This patient had decided early when they diagnosed him that he would die at home. His family all agreed with the discussion. The social worker visited with the spouse at home but they did not have rapport. The daughter and mother then approached the hospital social worker from palliative care to visit which he did. Good rapport developed and problem solving was initiated. The home care coordinator informed the director of nursing of the hospital that this was inappropriate and that the patient should be using the home care social worker. The social worker at the hospital was told by the D.O.N. that he could no longer visit the patient. The patient and spouse now were put in the situation of no support because of politics. Exactly where in this scenario did the home care grow and place the patient in priority. It was suggested early in this case, that the spouse should have someone in the house to assure comfort; and could be obtained when needed in the middle of the night or on weekends when the physician may not be available; or the drug store was closed. The spouse actually had to call the physician for these meds when needed. Home care nurses do not assess the patient's pain level. The final day of the patient's life when the pain was totally out of control and an IV saline block suggested by the physician, the family was told by the home care nurse that the patient would have to go to the hospital and was admitted. When the pain was under control, he could return home. The home care nurses could give support. A saline block was suggested as an alternative to the continued discomfort of subcutaneous

injections that the spouse was expected to give. When the home care nurse was asked how long it would take for a nurse to be called to give the subcutaneous injections so the spouse would not, the home care nurse said "if families want to keep their loved ones home to die, then, they would have to take some responsibilities." The nurses could not be available to give subcutaneous injections on a PRN and frequent bases. Should a family member feel responsible for the death of the loved one because he or she gave that shot just before he died? What is the home care nurse's role within the scope of his or her practice?

Same Letter -

Home care in a palliative care setting:

Home care cannot transport narcotics. The family and friends have to go to the drug store to pick up the narcotics to take it home even if the home care nurse is giving the treatment. If it becomes necessary to use injectable subcutaneous IN or IV narcotics for pain control, do not count on home care nurses to administer these. Family members will be expected to give the treatment. Home care may only visit twice a day. Home care nurses are available for support probably only twice in a 24hr day. Families not the nurses will be assessing pain and need to be educated about how to assess a treatment.

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