

Transcending Death by Living:  
Needs of Rural Manitoba Women Caregivers Providing Care  
for their Spouses (Common law or life partners)  
with Terminal Cancer at Home

by

Sandra Loraine Taylor

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

**MASTER OF SOCIAL WORK**

Department of Social Work  
University of Manitoba  
Winnipeg

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## **Acknowledgments**

I have learned so much in the process of working through this project and have been touched and supported by so many wonderful people. Without each of you, my experience would not have been complete.

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## **Dedication**

### **For my Mom**

Who does so much for her family.

She taught me how to be a woman in this world; to have passion for life and compassion  
for people and

she helped my dad, her partner and best friend, live his last days with support and  
comfort in their home and die with dignity in his own bed.

### **For my Dad**

Who, although is not alive to read this paper, remains deep in my heart. He taught me  
so much in life before his was cut short.

His unconditional love taught me that patience produces the best results and he  
continues to remind me how precious life is and how important it is to live each  
moment to its fullest.

### **For my Children**

Who may one day be in a position of supporting me or someone else in palliative care.

May they always remember the importance of caring for themselves in the process of  
offering support and care to others.

I love you all,

Thank you for being my inspiration to do this research and write this paper.

## **Abstract**

A qualitative study utilizing narrative research was conducted to identify rural women caregiver's support needs within the context of offering palliative care to their spouse (common law or life partner) at home with end stage cancer. Five women caregivers from three Regional Health Authorities participated in the study. Data was collected using in-depth semi-structured interviews. Three main categories of caregiver need were identified: communication, support system, and self care. As well, a gap in support of not having someone available to provide emotional and practical support and advocacy was articulated. Results from this study suggest the health care system could better serve women by being more aware of and responsive to women's needs, developing better communication, involving women caregivers as full team members, and developing a social work position within the palliative care team dedicated to providing emotional support, information, and advocacy to the female caregiver.

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## Chapter I: Introduction

In June 1999, my mother took a leave of absence from her job and went home to care for her spouse who had just been diagnosed with terminal cancer. For the next three months, she engaged in all the care giving responsibilities for him at home in a palliative care capacity and she did it, for the most part, alone. As I listened to her talk I was awed by what was going on for her and how she was handling things. Because of that, I became curious about what types of supports she had needed as the care giver. There appeared to be a lot of support for my father if he needed it, but nothing was offered to her except a small amount of home care.

According to Smith (2001), "with increasing numbers of terminally ill people remaining at home, family caregiving is [becoming] an important aspect of palliative care" (p. 83). Further, according to the Canadian Association for Community Care there are estimated to be three million informal caregivers in Canada and anywhere between 80% and 90% of home care needs are addressed by informal caregivers such as family and friends (Romanow, 2002). A caregiver is defined as a person bearing primary responsibility for and providing care for their dying relative (Wennman-Larsen & Tishelman, 2002).

Palliative care as defined by the World Health Organization (2005), Retrieved November 21, 2005 from <http://www.who.int/cancer/palliative/definition/en/>) has been adopted by the National Association of Social Workers in the NASW Standards for Palliative & End-of-Life Care (2004). They define palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Although there are a number of reasons why people are remaining at home, a significant one discussed by Neysmith, Bezanson, and O'Connell (2005) has to do with the political climate of the 1980s and 1990s. During that period, Canada underwent large economic and social changes. No sector went unaffected. In particular, health care sectors underwent massive reconstruction that saw the elimination of many resources

and with the change in health care policies, there has been a shift to home and community care.

As a feminist, I am interested in another significant element of caregiving, which is the person (usually female) who does the caring. There is a consensus that women are socialized and viewed by society as “natural” caregivers and “feel pressure to do this work for free (or rather at their own expense)” (Morris, 2004, p. 106) and this “gendered division of labour reflects economic and power relationships” (Baines, Evans, & Neysmith, 1998, p. 1). However, even though this consensus exists, “there is very little recognition of how restructuring [both society and health care in society] increases and changes the caring labour that women do and how these get played out in gendered, classed, and racialized ways” (Neysmith, 2000, p. 1).

Morris (2004) explains that resources for rural caregivers are minimal to non-existent. Rural areas tend to be more conservative and traditional, placing an even greater expectation on rural women to fulfill traditional roles as unpaid caregivers. The research also shows “caregiving primarily negatively affects the health of women rather than men, and interferes with women’s ordinary lives and plans much more so than men’s” (p. 106).

### ***Purpose***

The purpose of this research study is fourfold:

1. to understand the experience of women caring for their dying spouses (common law or life partners) in rural Manitoba;
2. to determine what women caregivers need in terms of caregiver supports in home palliative care;
3. whether those supports are available and if so, from what source;
4. what the quality of those supports are from the perspective of the female caregiver.

Put another way, the central question is: What do rural women caregivers say are their support needs when offering palliative care at home to their spouse (common law or life partner)? The hope is this study may be used as part of a continuum of research that tries to help health care professionals understand more fully the needs of the unpaid caregiver, and that public policies being made take more seriously the needs of women and incorporate their voices in policy decision making.

## Chapter II: Literature Review

### *History of Roles Played by Rural Women*

From the beginning, settlement of the rural Prairies by the Europeans has included a gendered division of labour that kept with the patriarchal homestead policies, ancestral traditions and the necessity of participating in a market economy that was a reality in Europe. These things continued to be important for the survival of the early rural settlers in Canada. Men signed homestead agreements, taking title to the land and began the work of creating income-generating grain farms. Their work was seen as valuable and important. As a result, a woman's role was to enhance the work and productivity of the men. All of their energy and time went into doing the tasks and roles that were seen as less important, but were necessary to keep men productive in the fields. The distinction between men's work and women's work conveyed value because the labour done by "the farmer's wife" was categorized as unproductive "housework" and so her claim on the family resources was less (Corman, 2005; Ferree, 1990).

The task of nurturing family members fell mainly to women. They were responsible for both the physical and emotional support of their entire family including her husband, children, and any elderly or sick that may have resided with them. According to Bye (2005), women's work included "work in the house and yard—cooking meals, washing clothes, cleaning house, tending children and sick adults, and

economizing by patching old clothing, sewing rag rugs, and generally 'making do'" (p. 144).

Bye (2005) writes that the gendered division of labour became even more enhanced during the Great Depression of the 1930s as women worked to hold family farms together in the face of falling economics and loss of income. They continued to support their husbands who worked in the fields trying to produce an income, even though the reality was that by 1937 in Saskatchewan two-thirds of the rural population was on government assistance. Women had to become even more resourceful in their unpaid and undervalued support of the family because the reality of many families became crop failure, poverty, illness, and dislocation.

Into the 1950s and 1960s farm women continued to balance their time around the needs of their husbands and children. Their days consisted of the routine domestic labour of cooking and cleaning, caring work, and assisting in the fields so grain and livestock could be raised and sold for income. However, according to Corman (2005), because their focus was on the family alone, women had the flexibility and time to structure their domestic labour throughout the day at times when other tasks were not the priority.

At the same time the early 1960s saw many rural women begin the move into the realm of paid employment as their urban sisters had done earlier. This had a significant impact on those women who continued to live and work on the farm and did not get pulled to live in urban centres. Schedules had to be created to fit in both the

paid work and unpaid work and that did not allow the same flexibility that women once had. At this time, "women were trapped in the contradictions inherent in holding paid employment while maintaining responsibility for household and caring work, and [women] faced inadequate state policies regarding childcare, elder care and safety issues (Corman, 2005, p. 70).

According to Corman (2005), today, in the new millennium, the world of paid employment has forced women to even more strictly organize their lives around the time requirements and other obligations of paid employment. This reality has offered women much less time and much less flexibility to assist their husbands in the fields, to care for themselves, and to do all the household and caring work. Yet, the expectation for rural women to continue fulfilling their traditional unpaid domestic labour and support of the family as well as contributing to the income of the family has continued.

As well, the turn of the century has seen some forms of women's work come full circle. Ferree (1990) highlights the continuity between work women did at home without pay in the early years and the jobs they then held in the paid work force. For instance,

nursing service was once part of housework, became a paid occupation, and is now being transferred back into the home as unpaid labour, as hospitals respond to cost-containment pressures by sending patients home "quicker and sicker" to be cared for by family members, primarily wives, daughters, and daughters-in-law (p. 875).

For rural women then, this means support they received from the paid labour force to fulfill some of their domestic labours such as caring for the sick within their family has been removed and they are again being required to fulfill these tasks unpaid. At the same time, many women will be doing these same tasks within the paid workforce, thus essentially doing double duty both professionally and personally.

### ***Caregiving and Palliative Care***

An extensive literature search shows although there is much literature related to “carers” and caregiving, not much is available with respect to “carers” and caregiving in palliative care and cancer within North America. According to Thomas et al. (2001) there is literature available examining the experiences of informal carers and family members connected with chronically ill people, but they say it is an area that is under-explored in cancer studies.

In the United Kingdom, several research projects have been conducted with respect to the needs of patients and carers in general and have offered conclusions about their needs and wants. According to Aoun, Kristjanson, Currow, and Hudson (2005) there are four types of family care needs that are consistently reported in the palliative care literature: patient comfort, information needs, practical care needs and emotional support. The National Institute for Health and Clinical Excellence (2004); Thomas (2003) and Thomas et al. (2001) summarize some of the research and indicate that when it comes to treatment, patients and carers want the following:

- To be treated as an individual, with dignity and with respect for their culture, lifestyles, and beliefs
- To have their voice heard and to be valued for their knowledge and skills and to be able to have real choice about treatments and services
- To receive detailed, high quality information about their condition and possible treatment, given in an honest, timely, and sensitive manner at all stages
- To know what options are available to them, including self-help and support groups, complementary therapy, health services, volunteer sector, and other information
- To have good face-to-face communication with health and social care professionals
- To know services will be well co-ordinated and of high quality
- To know physical symptoms will be managed to a degree acceptable to them and consistent with current clinical knowledge
- To receive emotional support from professionals who are prepared to listen to them and are capable of understanding their concerns
- To die in the place of choice
- To be assured that family and carers will be supported throughout the illness and in bereavement.

They continue to explain with respect to the caregivers specifically that because families and carers provide essential support for their loved one, they often do not recognize their own need for support. Often family members are busy trying to keep things as

normal as possible and so they remain “invisible” to health and social care professionals or it is difficult to get them to express their own needs which may be different from their loved one. They may need extra support at key times in the process such as at diagnosis, end of treatment, at recurrence, and around the time of death and bereavement, however, professional support is not always available for families and carers who need it.

Grant et al. (2004) acknowledge much research regarding caregivers has not been gender specific and has downplayed the impact of caregiving on women. For example the Romanow Commission in its chapter on home care specifically refers to women twice – once to say the burden of caregiving is great, especially for women, and the other to say that many female presenters such as the Pauktuutit – Inuit Women’s Association from Iqaluit, Nunavut and the Prince Edward Island Nurses’ Union in verbal presentations to the commission in April 2002, were concerned about the burden of caregiving on women. Romanow’s solution to the issue of burden is the recommendation of special leave administered through the Employment Insurance (EI) program (Romanow, 2002).

According to the Government of Canada (2008), claimants eligible for the EI Compassionate Care Benefit can receive up to six weeks of benefits. These benefits are paid out to one person, or shared among eligible claimants concurrently or consecutively, and the gravely ill family member must be at risk of dying within 26

weeks. Eligibility requirements for the Compassionate Care Benefit are the same as for EI sickness, maternity and parental benefits. The claimant must have:

- six hundred hours of insurable employment in the qualifying period, the 52 weeks prior to the start of the claim or, if a self-employed fisher, \$3,760 in fishing income; and
- an interruption of earnings or a reduction of more than 40 percent in normal weekly earnings (Retrieved April 17, 2008, from [http://www.hrsdc.gc.ca/en/ei/types/compassionate\\_care.shtml#qualifying](http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml#qualifying)).

However, because no gender analysis has been performed, it is not stated that many fewer women than men qualify for EI and thus for this special leave. This is because there is still a “gender gap” or a discrepancy in incomes in the Manitoba work force with women often making less money and more likely to be poor (almost 20%) compared with men (13.5%) and women are more often the primary caregivers of children and choose to remain at home and out of the paid work force (Donner, 2003). Also, some women who work full time in the workforce may have arranged to reduce their hours to part-time or take a leave of absence from their employment in order to perform some of the caregiving. Therefore eligible hours of work to qualify for this special leave may also become limited.

Qualitative research conducted by Smith (2001) from a caregiver’s perspective, focused on their roles and relationships with professionals tending to the care of the

person dying. Clark and Seymour (1999) speak about the potential for success of palliative care in the home. They say,

the degree to which palliative care needs can be met successfully in the home environment is shown to depend upon the close involvement and availability of an informal carer for the dying person. The provision of adequate support for informal carers, together with appropriate medical and nursing interventions, appears to increase the proportion of deaths that occur at home [as opposed to those that occur in hospitals] (p. 158).

The gap in knowledge then appears to be about the “adequate support for informal carers” from a gender analysis perspective. Studies have been conducted on the needs of the dying person; however, few studies have specifically looked at a female caregiver's perception of the quality of support offered to her as she cares for her dying loved one at home. Further, even fewer studies have been conducted that focus on a female spouse's perception of the quality of support she needed and received. Rena Miller's account of her personal experience in institutional ethnography research (Miller R. , 2005) is one such study.

As well, in a time when society begins to talk about self care and workplaces begin to take not only physical health but mental health seriously, we need to be cognizant that if a caregiver is giving beyond her health capacity, she may become of little use to her spouse (common law or life partner). Providing informal caregiving at home is a twenty-four hour a day job with few breaks. This has the potential to create serious health and social problems that may increase demands on the health care

system if we disregard the caregiver's need for support. In a study conducted by Sawatzky and Fowler-Kerry (2003) on the impact of caregiving by urban women, they found that in Saskatchewan,

Three out of every four caregivers are women, and as many as 10% of these are older than 75 years of age. While homecare services are available to assist in care, the burden of care often falls disproportionately on mothers, wives and/or daughters, who are unpaid for services. Physical effort, combined with lack of support, medical knowledge and sleep, can often place the health of caregivers at risk. It is estimated that 60% of caregivers have a health crisis after 18 months of caregiving (p. 277).

A search in Ovid of the Social Work Abstracts produced five articles on caregivers and palliative care. When "women" as a key word is added to the search criteria, no articles are found. Within the PsychINFO database, there were only two articles available using caregivers, palliative care, and women as key word criteria. One focused on significant others of women with early stage breast cancer, and the other focused on patient groups and whether different groups are disadvantaged with respect to home care access. Finally a search of the Social Sciences Abstracts (in psychology and health sciences) retrieved 120 articles or websites when palliative care and caregivers were used as criteria. However most of these articles related to institutional palliative care and/or formal caregivers such as nurses. When "women" or "female" was added to the criteria and a limiting factor of home palliative care, only one article was retrieved. This

article focused on female caregivers of people with AIDS in Southern Thailand.

Therefore, there appears to be a significant gap in literature within the social work field.

Literature that can be found within the social work field and palliative care seem to focus less on the caregiver and more on how the actual profession of social work fits into the system of palliative care or on the social worker in context with a patient.

Gwyther et al. (2005) offer an article on competencies required by social workers to work in palliative care. Issues such as knowledge, values, and skills are explored and described in detail. Brandsen (2005) looks at issues such as core principles (self-determination, common good, and holistic care) required by social workers to work within the palliative care team and being able to relate to those dying and their families. She also looks at barriers encountered by social workers within the current system. Both of these articles originate from the Social Work Summit on End-of-Life and Palliative Care conference held in 2002 at Duke University in North Carolina.

The National Association of Social Workers (2004), in the United States, building on the foundation of the Social Work Summit has developed standards of practice relating to palliative care and end-of-life. In this document, social work is defined as a broadly based profession that has the opportunity to meet the needs of clients, families, and caregivers. This document articulates the need for social workers to be an integral part of the health care team.

Social workers should advocate for the views and needs of individuals and families in palliative and end of life care within the team, and should

encourage and assist clients in communicating with team members. Often, clients, families, and team members rely on the expertise of the social worker in problem solving concerns and conflict resolution (p. 24).

According to a study conducted by Lloyd (1997) (cited in Small, 2001), social workers saw themselves as advocates fighting to keep the “whole person approach” because of the growing emphasis on case management at the expense of counselling. Lloyd indicated a joint statement issued by the British Association of Social Workers and the Association of Hospice and Palliative Care Social Workers that supported that fight. The statement issued said “a quality service for terminally ill people must reflect a psychosocial approach and that the social worker will contribute to the multidisciplinary team” (Small, 2001, p. 968).

A study conducted by Guo, LeDay-Jacobs, Palmer, and Bruera (2007) focusing on the cancer patient discovered that although social workers are regularly consulted to assess coping and support for the patient, their actual role in the cancer setting has not been described. The findings of their study concluded that “a social worker provides patients with social support, including counselling and referral to other resources, which plays an integral role in maximizing the patient’s rehabilitation potential in a cancer center setting” (p. 200).

Oliviere (2001), Sheldon (2000) and Small (2001) all address the issue that the role of the “specialist” social worker in palliative care has been poorly researched and

yet is very important. Sheldon's research contributed a conceptual framework for the role of the social worker in palliative care consisting of six key elements. These include:

- a family focus
  - focus on family relationships
  - enabling family communication
  - planning for the future
- influencing the environment
  - advice, information giving
  - organizing finances
  - liaising with and supporting colleagues
- being a team member
  - modeling for the team
  - handling disagreements
  - managing tensions between confidentiality and sharing
- managing anxiety
  - family
  - the professional team
  - individual
- values and valuing
  - being non-judgemental
  - encouraging self-determination
  - normalizing and challenging discrimination
- knowing and working with limits
  - assessing
  - creating safety for the clients
  - promoting open discussion

This framework resonates with commentary done by Small (2001) whose focus was to bring together contributions made in social work and palliative care to help create an understanding of the function social workers play. He indicated that there is a disagreement of views between those who believe that roles overlap and blurring is essential for effective multidisciplinary teams in palliative care and those who believe the unique role of the social worker should be maintained (Clausen, Kendall, Murray, Worth, Boyd, & Benton, 2005). According to Small,

in terms of the overall rationale for the place of social work in palliative care it is argued that:

- social work has always been concerned with responding to loss;
- it brings a whole system view, putting individual experience into a wide context; [and]
- social work has a concern with helping ameliorate the practical impact of change – for example in relation to finance (p. 963).

Finally Oliviere (2001) looks at the “eccentric” role of the social worker. He says that social work is very context-determined. By this he means the role of the social worker is to work with the whole person within their own context. This context may consist of family, neighbourhood, community, and society. As well, things such as organizational policy can determine the roles a social worker will play. Within palliative care then, it is the role of social work to respond to the different contexts in which they practice and continue to advocate for a community and family perspective always keeping the “social” piece of social work in mind.

The nursing field on the other hand has been looking at this type of research for a number of years and has done so from a number of different perspectives. A search of CINAHL reflected a few more articles on palliative care, women, and caregiving. However, according to Bailey, Froggatt, Field, and Krishnasamy (2002), although nursing has been a key contributor to qualitative research in palliative care accounting for 48.6% of articles reviewed in their study, in actuality “only limited attention had been paid to research in palliative care” (p. 50) as only a total of 138 articles were found that met the criteria of both palliative care and qualitative research. Boulton, Fitzpatrick, and Swinburn (1996) investigated seven medical journals over a 5-year period, and identified 70 papers out of a total of 3573 (2%) that met their criteria for qualitative research (such as grounded theory, phenomenology, and narrative research) within the field of palliative care. A study by Buehler and Lee (1992) found in a study of people who had cared for family members dying of cancer while living in a rural setting that the greater the deterioration of the ill person and the longer the dying process took, the more the families saw their role as difficult and perceived resources to be inadequate.

In a grounded theory study, Proot et al. (2003) explored experiences of family caregivers, their needs for home care and which health services they received. They identified “vulnerability” as the core category. They stated that there is a continuous balance between care burden, including caregiver fatigue and eventual burnout, and the capacity to cope. An inability to cope was often determined by the lack of support from “health providers” and was demonstrated when “professional care and/or aids are not available, and continuity of care is not guaranteed” (p. 117). In another grounded theory

study balancing was seen as the fundamental process. In this study, both caregivers and patients were interviewed and the balance between caregiver resources and the needs and wishes of the patient were discussed (Thulesius, Håkansson, & Petersson, 2003).

Wennman-Larsen and Tishelman's (2002) article articulated that although the participants saw the dying person being at home as an important and valuable aspect, they had little expectation of professionals to assist them at home. The caregivers generally expected to be fully responsible for daily care tasks and if professionals were to be involved, care would be focused on specific things related to the dying person. As well, although family caregivers addressed needing someone to talk to under the theme "transition to a new life situation of the caregiver" (p. 244), no one ever mentioned health professionals as possible sources of emotional support for themselves.

Research in Canada that has focused specifically on the needs of the caregiver has tended to focus on programs already in place such as respite care. Strang, Koop, and Peden (2002), in their interpretive qualitative study at the University of Alberta, focused on how family caregivers experienced respite within home-based palliative care. They discovered that although caregivers were offered a physical break and accepted it; it did not necessarily constitute a mental break. Caregivers tended to differentiate between respite and "having a break". They said that for them respite was more of a rarely achieved mental state "which resulted in feelings of freedom from responsibility for and worry about caregiving" (p. 100). However, caregivers also indicated that taking mental breaks was necessary during the dying process. These times happened in small intervals

but occurred while still in close proximity to their dying loved one, sometimes by reading, watching TV, or meditating.

There is clearly a gap within research in the area of women offering palliative care at home to their spouse (common law or life partner). Research offers material about caregiving by husbands, wives, daughters, sons, and good friends, all within the same study (Andreassen, Randers, Näslund, Stockeld, & Mattiasson, 2005; Proot et al., 2003; Singer, Bachner, Shvartzman, & Carmel, 2005; Soothill et al., 2001). It was not possible to find a gender analysis of caregiving to really explore issues related to rural women, who provide informal care. We need to examine the extent to which key variables such as gender influence home-based palliative care experiences for rural women. Because women by the very nature of their socialization are often the nurturers of the family, they are more likely than not to be the one called on to do much of the hands on caregiving at the end of life.

As well, in a field where cooperation with other disciplines is necessary, social work is lacking in the area of researching palliative care and caregivers. It is important that we increase our research to join that of professions such as nursing, so our perspectives are taken into consideration as programs are implemented and we continue to take part on teams of professionals offering support during the palliative care process. The role of social work within palliative care teams is in a time of redefinition. According to Brandsen (2005), it is an appropriate time to assess the profession's contributions to this field of practice, to bring fresh ideas and leadership to

end-of-life care, as well as to find our place within practice, research, education, and policy development.

Additionally, research from a social work perspective is needed in this area so that policy makers can be more fully informed of what social workers have learned about the needs of the caregiver offering palliative care. "Pressure must be brought to bear on politicians and policy makers to expand resources to home care palliative care programs, so families can adequately and humanely be supported in their labour of caregiving" (Strang et al., 2002, p. 103).

### ***Drivers of Caregiver Satisfaction in Palliative Care***

Research surrounding caregiver satisfaction in palliative care has shown a significant correlation between feelings of support for self and a successful death. Research suggests communication; knowledge and access to information; and emotional support are three substantial themes constituting support for a caregiver. According to a study conducted by Jansma, Schure, and Meyboom de Jong (2005) when it came to the kind of supports caregivers need, the results showed communication rated the most important at 30%, followed by practical information at 26%, and third by the caregiver's health at 17%.

***Communication.*** Several early studies conducted looked at the interaction between health care providers and caregivers/family members. Consistently, those studies have shown problems with communication between the family and the health

care professionals (Kristjanson, 1986; Northouse & Northouse, 1987; Stedeford, 1981). According to Stedeford (1981), next to uncontrolled pain, poor communication caused the most suffering for cancer patients and their families.

According to Hearn and Higginson (1998), in a review of literature focusing on specialized palliative care teams in the United States and United Kingdom, evidence suggesting that “poor communication results in dissatisfaction and increased co-morbidity of both the cancer patient and their family or carers” (p. 319). They suggest that an effective and communicative team is seen as an essential element for achieving “effectiveness in palliative care”. This effectiveness is judged in terms of “the quality of life before dying, quality of life at the time of dying, a ‘good death’ and the impact on the family or carers” (p. 319). As well, McIlpatrick (2007) identified the need for improved communication within the health care system. McIlpatrick states “some possible barriers and examples of poor communication included difficulties in discharge from acute to community care; lack of co-ordination between members of the primary healthcare team; problems with out-of-hours service provision; and a sense of constantly struggling with ‘the system’” (p. 83).

Thompson (2007), who researched caregiver satisfaction in personal care homes, states that communication establishes the importance of involving family members in decision making, communicating what to expect at the end of life, and taking the time to really listen to the caregiver. When offered these things, caregivers felt satisfied with care. However, Thompson says it is discouraging because in her study only “27.6% had

received information on what to expect when the resident was dying, 25.3% had received information on what to do at the time of the resident's death, and 12.6% had a staff member talk to them about how they might feel after the resident died (p. 165). Further Phipps and Braitman (2004) indicate that caregivers of persons who died at home were seen to be less satisfied with the communication from service providers than those caregivers whose loved ones died in hospital or hospice.

Overall, communication ranks high within most studies relating to satisfaction in palliative care. According to Wenrich et al. (2003), "there is a strong ethic that patients need to know the truth about their terminal illnesses; in fact our work concerning communication confirms that patients say they want honest and straightforward information about their illness" (p. 244).

***Knowledge and access to information.*** Knowledge and access to information was seen in the literature as extremely important to caregivers and was diverse in substance. Again, earlier studies by Bond (1982); and Kristjanson (1986) found that obtaining adequate information from health care professionals was difficult and problematic. Such things as problems contacting physicians, being refused information, or in acute care settings having to seek information from staff unfamiliar with the situation added to the problems and family member's frustrations of having access to information. According to Thielemann (2000) and Wei-chun Lin and Chao-jung Tsao (2004) caregivers primarily wanted information about the disease their loved one was experiencing; the care of their loved one, including physical care (such as dealing with

pain and helping the loved one to be more physically comfortable) and emotional issues (such as dealing with difficult symptoms and changing perceptions); how to care for themselves; and accessing community supports. In addition, women regarded information on psychosocial supports as more important than men did.

According to Wingate and Lackey (1989) [as cited in Wei-chun Lin and Chao-jung Tsao (2004)]

family members need the “knowledge, information, or understanding that can be gained through education, experience, or study, or through assistance by explanation.” Having these needs met has resulted in improved patient care over the progression of the disease due to more effective caregiving. The three most frequently identified categories of important information pertained to dealing with the illness itself, meeting the physical needs of the patient, and locating community resources. Another important information source for caregivers is advice from psychologists and social workers on improving the emotional and physical condition of both the patient and themselves (p. 438).

However, according to Thompson (2007) and Thielemann (2000), many studies identify a lack of information about available resources and this is seen as a problem for caregivers. Caregivers are often dissatisfied with care when there are inadequacies in the quality of information, the way in which information is delivered or the lack of information all together.

Further, Wei-chun Lin and Chao-jung Tsao (2004) and Thielemann (2000) indicate that caregivers often have a difficult time articulating their needs. Perhaps this

can be explained by Abraham Maslow's hierarchy of needs theory (Davidson, Cockburn, Daly, & Fisher, 2004). Research indicates that the physical needs of the loved one is the most important priority and only once those are satisfied can the caregiver focus on social, emotional, or spiritual issues.

***Emotional support.*** Finally emotional support of the caregiver is important through the caregiving process and after death. According to one study, emotional support ranked second after communication in importance for caregivers of palliative care patients. Within this study, emotional support was comprised of four components: compassion, maintaining hope and a positive attitude, providing comfort through touch, and being responsive to patients' emotional needs (Wenrich et al., 2003). According to Thompson (2007) and Wenrich et al. it is important for formal support people to take care to develop trusting relationships with both the caregiver and the loved one. To do this, it is necessary to acknowledge that what the loved one is going through is significant and respond to issues as they are raised by the loved one or caregivers. By ensuring individualized treatment and care for the entire family, taking time to listen to concerns, providing education and encouraging decision making, a caregiver's emotional status becomes less stressed. This then helps with the caregiver's anxiety and stress level and gives a more positive outcome on a caregiver's energy level and overall health. In the study by Wenrich et al., one participant who happened to be a loved one articulated the way in which emotional support can be offered. They said by asking one simple question beyond all the other usual questions, this support becomes obvious

My doctor says, "How are you feeling?"  
And I say, "Well, you've got the charts."  
And he says, "No, how are you **feeling**?" (p. 240).

### ***Theory of Coping and Resiliency by Women***

Although a gendered division of labour has resulted in women doing a significant amount of the caregiving of sick and dying persons, it is important to consider the human strengths and resiliency that help women continue moving through the caregiving process. It is often in the event of negative life events, suffering, and personal loss that human strength and resiliency is best illustrated. Further, research has shown that resilient people have entirely unique ways of coping with life-threatening illnesses (Glicklen, 2006; Miller E. D., 2003).

In 1984, Lazarus and Folkman in their book *Stress, Appraisal and Coping* articulated that stress could be thought of as a result of an "imbalance between demands and resources". They developed a transactional model of stress management – Stress and Coping Theory – with the ideas that the person and the environment are in a dynamic, mutually reciprocal relationship and that stress does not occur as a direct response to a stressor, rather it is a response to a combination of one's resources and their ability to cope with the stress. When these factors are combined together, stress can be navigated and controlled. (Lazarus & Folkman, 1984; Pakenham, 2001).

The model Folkman (1997) articulates, begins with an event that represents the precipitating factor leading to stress (for example, the female caregiver's receipt of a diagnosis of cancer for her spouse). That event then branches off to two different types of appraisal. On one hand, a person may find the event to be benign or irrelevant and if this is the case, there is no coping necessary. On the other hand, a person may analyze the event as a threat, challenge, or potential harm. When the event is seen in this way, stress is created that needs to be coped with. Coping strategies are then implemented that may include problem and/or emotion focussed coping. These strategies then lead to an outcome. When that outcome is considered positive, the caregiver is seen as having a positive emotion, however when there is an unfavourable or no resolution, distress continues in a feedback loop back to the appraisal column.

According to family stress theory, a family is a social system and therefore stress in one family member has a reverberating effect on other family members and as a result supportive care is needed for all members of the family in response to an illness such as cancer.

The theory also suggests that in times of illness, families must adapt to both normative (e.g., developmental) and non-normative (e.g., illness-related) changes and that a combination of these stressors can accumulate and exceed the family's coping resources. Family stress theory emphasizes the importance of identifying family strengths that can be used to help families adapt to hardship and strain (Northouse, et al., 2002, p. 1412).

Within the past number of years then, social work has begun to move from a problem focused perspective to a more strengths based perspective when working with individuals, taking into consideration an individual's ability to cope with adversity in life and to be resilient. "The strengths approach uses people's own resources to help them meet four goals: (1) to grow as human beings, (2) to improve their quality of life, (3) to develop their own problem-solving skills, and (4) to deal with their stress and adversity" (Heinonen & Spearman, 2006, p. 217).

According to Heinonen and Spearman (2006), to be resilient is "the ability to bounce back from traumatic and difficult life experiences" (p. 228) and Schoon (2006) continues by stating "resilience is a dynamic state depending on the transaction between a developing individual and the socio-historical context experienced by the individual" (p. 121). At the same time, coping refers to "efforts to master conditions of harm, threat or challenge when a routine or automatic response is not readily available" (Monat & Lazarus, 1977, p. 8).

Although women face a seemingly endless supply of challenges while caring for their loved one, according to research, they also have resources, knowledge, skills, and competence to call on in times of distress. In a review of the literature, a number of studies have been found to support the resiliency and coping capacity of women.

Schoon (2006) investigated the connection between success in any area of life and an increase in self-esteem and a belief in oneself. By experiencing that success, it was found that an individual [woman] is more likely to feel more confident to handle

new challenges and then have the capacity to act in a way that is helpful to both her and her family. Schoon further argued that often success for women was accompanied by a number of things that had occurred in childhood. Women who had access to a positive academic experience and experienced academic resilience were found to be better able to cope with difficult transitions. Also, women who were socially advantaged as children and young adults were found to have better psycho-social adjustments and patterns of partnership and family formation than women from disadvantaged backgrounds.

A study by Leipert and Reuter (2005) looking at women's ability to maintain their health in isolated communities found

Establishing self-reliance increased women's confidence, courage, and skills to tackle new and difficult challenges, thereby increasing their abilities to take care of themselves. Establishing self-reliance meant taking responsibility for oneself by developing new, or enhancing existing, abilities and opportunities to counter isolation and limited options (p. 57).

Although this sounds relatively straight forward, Abrams (cited in Glicker, 2006) notes, "clearly, some family members have greater inner and outer resources probably due in part to genetic endowment, intergenerational forces, role in the family, relationships with family and friends, early life experiences, quality of nurturing, and social supports" (p. 132). Therefore establishing self-reliance when taking care of a terminally ill spouse (common law or life partner) comes with the need to have much resilience and support.

Some of that support for woman may be found in other supportive family members. A study by Barnas and Valaik (cited in Glicken, 2006) found that women who had positive attachments to adult children and other significant persons had a better ability to cope with stress both physical and emotional. Women with poor attachments appeared to suffer more anxiety and depression thus creating more vulnerability and stress in their life.

Finally Glicken (2006) discusses a number of attributes women may possess that add to their ability to cope and be resilient while taking care of their spouse (common law or life partner). Such things as flexibility; adaptability; a sense of humour; financial, social, and organizational skills; an ability to find meaning in crisis situations instead of simply managing them; an ability to shift priorities to accommodate change; and a sense of mastery all contribute to a woman's ability to cope and be resilient. However, it is also important to understand that women caregivers can be in the unique position of being a caregiver and needing care and although they are resilient, women may actually have unmet needs that go undetected because they are perceived as doing well. According to Harding and Higginson (2003) "current provision for informal carers has been described as crisis intervention, in that services ignore successes and reward failure" (p. 63). That is, services are not provided to caregivers who appear to be coping well, but are provided to those who are not.

## ***Summary***

Traditionally, women have been the caregivers of the young, old, and sick in the family. Through history, this role has remained relatively consistent even as other responsibilities such as moving into the paid workforce have changed. Women have therefore become less flexible in their daily lives as they conform to the paid work force. Support they garnered when care of the sick was moved into the paid realm is rapidly deteriorating as the health care system attempts to stabilize ill persons and move them quickly back into the community, thus returning the responsibility for caring back to the unpaid labours of women.

Although women have taken the majority of the caregiving role, there appears to be a gap in knowledge when it comes to women caregivers in the palliative care system working with cancer. Many studies have been conducted focusing on the needs of a terminally ill person and several studies have looked into the needs of carers in general, however, no study has specifically looked at the needs of a female spouse caring for her husband (partner or common law) at home. Further, studies that have been conducted in Canada have tended to focus on already existing programs such as respite and have not delved into specific needs women may have. From a social work perspective, very little research has been conducted in the area of palliative care and caregiving. Most research has tended to focus on how the profession fits into the system of palliative care or its relationship with the patient and families. Therefore it is important that this

profession steps up and contributes to the research knowledge to ensure the profession can be a valuable part of palliative care teams as they develop.

More general research conducted with caregivers in palliative care has looked at what satisfies caregivers in the palliative care process. Studies have shown communication is the number one determinant of caregiver satisfaction. When communication with health care professionals is successful, the stress of caregiving is less and this contributes to an increase in satisfaction. However, most studies report a lack of communication between patients, families and health professionals. A part of communication for caregivers is access to information. Several studies have shown that caregivers want access to accurate information; however, often have difficulties in retrieving it. Also, many times caregivers are unable to articulate their own needs perhaps due to the everyday demands of caring for their loved one. Emotional support in one study came second only to communication in what was important for caregivers. Having someone who listens to their concerns, offers hope and a positive attitude, and comforts both them and their loved one was important to caregivers.

Finally, although women are challenged with many different tasks, issues, ups, and downs in the caregiving process, their resiliency seems to be strong in most cases. According to research, women have an ability to draw on skills, resources, coping techniques, and knowledge to help them continue and pull them through difficult times. This strength helps as women work to problem solve and balance life as it comes.

### Chapter III: Methodology

While there has been research conducted about caregiving in areas such as respite (Strang, et al., 2002) and among nurses and other professional caregivers (Bailey, et al., 2002) there is a lack of research especially in the social work field about rural women caregivers providing palliative care at home. Social work research has tended to focus more on the profession itself and how it fits into the palliative care process (Brandsen, 2005; Gwyther, et al., 2005; Rodway & Blythe, 1992). The intent of this research is to understand the experiences women caregivers undergo, and to hear and understand what supports women caregivers need and if those supports are currently available, what is their quality.

I have chosen narrative research as the methodology for this study. A narrative research approach, according to Fraser (2004), has much to offer social work. "For a start, they [narrative research studies] provide ways to make sense of language, including that which is not spoken ... and they are able to authorize the stories that 'ordinary' people tell" (p. 181). Narrative also allows social workers to better understand how knowledge is constructed through ordinary language (Riessman & Quinney, 2005). This will allow the words of the women to be spoken and understood in conjunction with existing literature by adding fresh ideas, needs, and insights instead of simply supporting or refuting that which is already published. As well, by empowering women to tell their stories, narrative research offers a chance to contribute to research when

there is a gap in knowledge, especially when the gap involves the voices of those most directly affected.

### ***What is Narrative?***

According to Denzin and Lincoln (2000), narratives have included many different theories since the beginning of qualitative research. However in the past number of years, the notion of, and interest in narrative research and its application to human and social sciences has meant beginning to really define what narrative is (Elliott, 2005).

At its most concrete, Webster, 1966 (cited in Lieblich, Tuval-Mashiach, & Zilber, 1998) defines narrative as a “discourse, or an example of it, designed to represent a connected succession of happenings” and narrative research according to Lieblich et al. (1998) “refers to any study that uses or analyzes narrative materials” (p. 2). However, this is only one definition and as interest has grown, different disciplines have found their own definitions that make sense to them. Therefore it has become increasingly difficult to establish a single definition for narrative or a narrative approach to research.

The term narrative has over time come to mean anything and everything according to Riessman and Quinney (2005). “To put it simply, when someone speaks or writes spontaneously, the outcome is now called narrative by news anchors and qualitative investigators alike” (p. 393). At one end of the spectrum, narrative is seen in the broad sense as an entire life story obtained from sources such as interviews, observations and documents. This definition is often used by disciplines such as

anthropology and social historians. At the other end of the spectrum lies a very restrictive definition used by sociolinguists where a specific question is answered in the form of a story through the use of a specific discourse (Riessman & Quinney, 2005).

Somewhere in the middle is the continuum of definitions of narrative that fits for the area of social work and will be used within this research. Here, narrative includes long sections of talk through one or more interviews that put a person's story into context. In this definition, there are three key features describing the narrative. They are chronological (a sequence of events), meaningful, and social (created for a specific audience) and cannot be understood outside that social context (Elliott, 2005; Riessman & Quinney, 2005).

So although there has been a narrowing of definitions to fit specific disciplines, it is important to recognize there is no clear cut definition for narrative. What does make narrative unique is understanding how and why events make it into a story and not simply focusing on the content. Understanding what the sequences of events are and how "consequences" are connected and evaluated is the distinguishing factor of a narrative approach. By understanding that the narrative has a beginning, middle, and end and that we construct the stories in relation to our social environment, a researcher can work to explain a particular event or to complete a story (Riessman & Quinney, 2005; Murray, 2003).

### ***The Narrative Research Approach***

A growing interest in a theory of narrative research, especially within the social sciences, can be traced back to the early 1980s. Within the field of sociology, there was a growing concern that research was not being read or seen as being interesting because of the way it was presented (without the use of statistics or other specific information). It was during this time then that Bertaux, in Europe, and Mishler, in the United States, began to look at the need to focus on individual stories and interviews to find meaning and context in research (Elliott, 2005).

The 1990s then saw momentum generated for doing and understanding narrative research. Journals such as *Narrative and Life History* (now *Narrative Inquiry*) were established. Those publications along with writers such as Clandinin and Connelly (2000) began writing on a narrative approach to research and established another methodological way of doing qualitative research. This has led to research using a narrative approach in numerous different areas including health, specifically chronic disease, AIDS, and epilepsy; health behaviour and health education; and criminology (Elliott, 2005; Creswell, 2004).

In narrative research, according to Creswell (2004), the researcher describes the lives of individuals, collects and tells stories about people's lives, and writes the narratives of an individual's experiences. The narrative typically focuses on studying a single person, gathering data through the collection of stories, reporting the individual experiences, and discussing the meaning of those experiences for the individual.

As narrative inquiry and narrative research continue to become a more common methodology within qualitative research, Elliott (2005) offers five themes that remain prominent in research that pays attention to the narratives or stories of respondents.

1. An interest in people's lived experiences and an appreciation of the temporal nature of that experience.
2. A desire to empower research participants and allow them to contribute to determination of the most salient themes in an area of research.
3. An interest in process and change over time.
4. An interest in the self and representations of the self.
5. An awareness that the researcher him- or herself is also a narrator (p. 6).

Caring for a spouse (common law or life partner) into death is an intimate and personal experience, and since I have never experienced this aspect of life, my world view as a researcher alone cannot do justice to the participant's experiences. Listening to and really hearing the voices of these women from their world is to give power and authenticity to their experiences. This research is based on hearing and telling the stories from the caregiver's perspective and by doing so, helping women, professionals, and policy makers really begin to see into the world of the female caregiver and her needs and wants as she cares for her dying spouse (common law or life partner).

I wanted to hear the stories of rural women who have cared for their spouses (common law or life partners) as they went through the dying process at home, but more than just the stories, I wanted to understand the experiences of their caregiving

and how their supports or lack of supports reflected their experiences. In hindsight, did the women think there were supports or resources that would have made their situation easier to work or cope with, or more manageable during their caregiving time? Narrative and description can be extremely useful according to Keddy, Sims, and Noerager Stern (1996) and can be used to advance policy and political agendas. From a feminist standpoint, this is a political issue. Solid narratives can offer more power and pull in the social policy arena which is where my research is intended to make a contribution.

### ***Validity and Reliability of the Design***

Validity or validation of narrative analysis remains an unsolved dilemma even though there is a growing amount of work being done on validity and reliability within qualitative research. Questions remain about how to evaluate narrative analysis because it may be difficult to decide whether one piece of research is better or worse than another. Establishing validity relies on realist assumptions; they are in many ways incompatible and irrelevant to narrative research. However, it is possible to pay attention to such things as the stability, the trustworthiness, and the scope of the findings as a way of looking at validity and reliability (Elliott, 2005; Riessman, 2002).

One of the advantages of narrative based research is the use of personal interviews and the focus on how each of those interviews serves as a basis for the meanings participants make in their lives. Because participants are encouraged to be specific and concrete about details in their stories, the validity of the research is

naturally strengthened. However, at the same time a caution is urged because in order to create the story, participants are asked to reflect on what occurred. Therefore by virtue of what the women choose or remember to tell the researcher, they have the ability to select what becomes part of the story. It is therefore important that the participant be responsible for the narrative to ensure perspectives reflect their voice and not the voice of the researcher (Elliott, 2005).

A clear audit trail was important throughout this research; how data collection occurred (digital voice recording and journal notes), and how analysis was conducted was documented. Also, descriptions of the participants including such factors as ethno culture, age, sexual orientation, and class have been made accessible to the reader. A comment about those who volunteered to be interviewed but were not interviewed was added with a brief explanation as to why they were not chosen. By offering this information, the research process becomes transparent. As Padgett (1998) says, "leaving an audit trail means adopting a spirit of openness and documenting each step taken in data collection and analysis" (p. 101).

Evidence of researcher's self reflection offers transparency and an ability to follow the decisions I made. Clearly articulating my social location can affect how questions are worded and asked, and my perceptions in analysis. Readers can become aware of my biases. According to Finlay (2002), reflexivity should begin in the pre-research phase, as the project is being conceived. I am the daughter of a caregiver and watched and contributed to the caregiving process. This means I already have some

preconceived notions about what supports may have been helpful to my mother as the primary caregiver. By articulating this, I can ensure I am aware of how I may be trying to have similar supports be important to participants. Also, because I am working from a feminist perspective, it is important that I recognize how this social location may influence the data both in collection and interpretation. How I asked questions, what further probing questions I asked, and what information I chose to follow up on or analyze may be influenced by my feminist philosophy. However, "through the use of reflexivity, subjectivity in research can be transformed from a problem to an opportunity" (Finlay, 2002, p. 531).

Finally, from a feminist standpoint, it is important that it be clearly stated how I attended to my relationship with the research participants. It was essential to ensure I was clear about my relationship to the participants, what I had in terms of ability, resources, and time to offer. Each participant was given a list of accessible resources through their local Regional Health Authority in the event a woman needed counselling or further support after the interview. Because these local supports were automatically given out, I am not aware if any woman needed or accessed any further support. As well, interviews were left to the discretion of the interviewee in terms of time, location, and determination to cease at any point. Four interviews took place in the woman's home and one at the local palliative care office. All took place within their home town. As a professional social worker, I needed to be attentive to a woman's potential need to debrief issues that surfaced for her and offered her that opportunity at the time of the

interview and provided information about free resources for longer term needs.

Attention to this ethical obligation also adds to my credibility as a researcher.

The use of an audit trail made moving back and forth through my analysis much easier and I could continually reflect on how I was interpreting and analysing information. This also helped with respect to my own reflections throughout the process. As I traced my own reflections through the study, for example how I felt as I listened to each story and when I re-listened to them or read transcripts the audit trail helped me ensure I remained authentic to the participant's words and that my bias was not overtaking the analysis. When I spoke in the beginning with each participant, part of my explanation of the process was to talk about why I chose to do this research. It was at that time I chose to tell them how palliative care and death has touched me through my father. I felt that being transparent about that created a connection that helped in creating a positive and supportive environment for the interviews to occur. The women said that they felt some of the information they shared I would understand because I had been in similar situations. Also, each woman expressed their appreciation for the support they received to tell their stories and were grateful for the resources made available to them. Although each woman felt they would be alright after the interview, a number expressed how it was nice to know there was enough care and thought about what may surface later that local resources were given.

### ***Criteria for Research Participants and Recruitment Process***

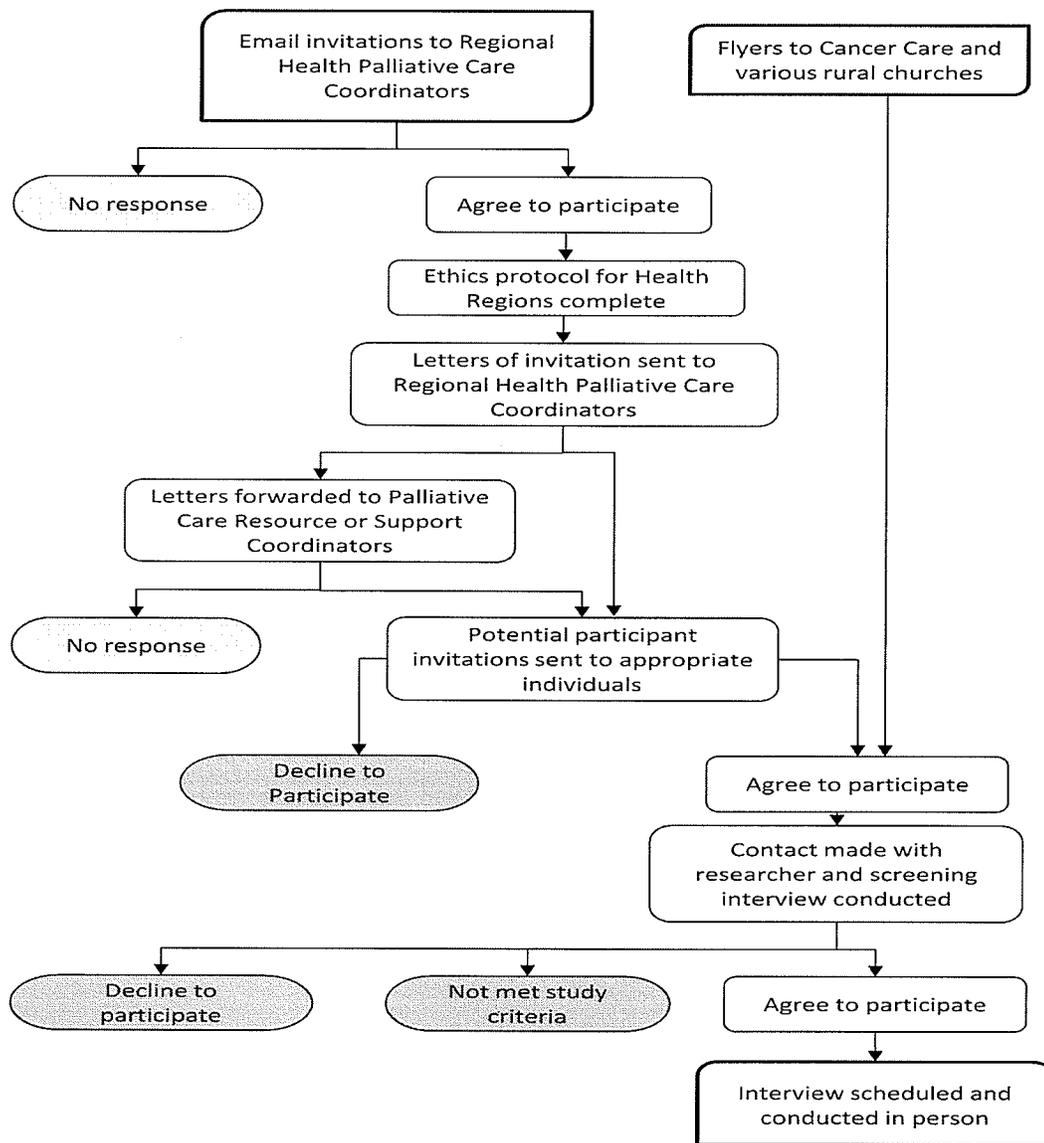
My intent was to obtain data from six to eight women who provided palliative care in different rural settings within Manitoba. I targeted six health regions including Assiniboine, Central, South Eastman, North Eastman, Interlake, and Parkland (see Appendix A). I was open to speaking with women of all backgrounds, including socioeconomic status, culture, and sexual orientation as long as they were able to speak and understand fluent English; however, because of the complexities associated with people living on reserves in Manitoba such as healthcare funding provided by the federal government perhaps leading to an even further lack of resources and many other compounding issues, I excluded this population from my study. My intention was to include women who had provided palliative care between one and five years prior to the date of the interview thus offering a significant period for initial grief but a short enough time that detailed information would still be accessible.

Ringdal, Jordhoy, Rindal, and Kaasa (2001) studied close family members of people who had died of cancer and found their grief and bereavement intensified slightly up to three months after the death, but then steadily declined up to 13 months post death. They found that beyond 13 months, although grief and bereavement continued, most people were back to feeling functional in their prior and new found roles. This supports the understanding then that a year allows women the time necessary to move through all the firsts that come after a death. By using five years post death as participation criteria, my hope was to offer enough time so the women can tell

their stories, but not have so much time pass that details are lost, re-interpreted, or significantly changed, or that women simply forgot what was or may have been helpful during the process of caregiving.

Figure 2 illustrating the sequential flow of participant recruitment can be seen below.

Figure 2: Flowchart of Recruitment Protocol



Participant recruitment began in a number of places. Flyers were posted at Cancer Care Manitoba and also sent out to a number of United and Lutheran churches in the area surrounding Winnipeg which included information identifying target groups desired and advertising the research (Appendix B). Professionals such as Palliative Care Team Coordinators; Palliative Care Psycho/Social Coordinator; or Regional Practice Leader Palliative Care in each of the targeted Health Regions were contacted first by email requesting support and help in recruiting potential participants. Once a response was received, the necessary paperwork for their ethics review committees was completed (see Appendix C) by myself and returned for Health Region approval. A package was then sent out containing the professional contact letter (Appendix D) asking for support in linking potential participants to the researcher; four letters for potential participants (Appendix E) to be given to people meeting the research criteria; and an extra flyer.

In some cases these coordinators did not provide direct service and therefore did not have the best knowledge of appropriate and potential participants. In these cases, the professional and potential participant letters were forwarded to the Palliative Care Resource or Support Coordinators in local areas for appropriate distribution. This allowed for complete confidentiality for potential participants. Although there was a request for at least four potential participants to be identified in each participating Health Region, only those potential participants interested became known to the researcher when they made contact.

In the end, I was successful in contacting five of the six targeted Health Regions. After the first contact, I recruited less than full capacity of potential participants. Therefore I contacted these five Health Regions again to ask for a second attempt at recruitment. The combination of these two processes produced a final total of six potential participants from three health regions.

When contact was made with a potential participant via phone, a brief screening interview took place (see Appendix F). Once it was determined they met the research study criteria, an in person interview was scheduled including date, time, and place. In only one instance, a potential participant did not meet the research criteria and was therefore not able to participate in the study.

### ***Data Collection Procedures***

There are several different methods of data collection that can be used in narrative research. The stories of experience are shaped by the collaboration of the researcher and the research participants and this relationship may be made up of a number of different methods of data collection. Data can be found in field notes, journals, interview transcripts, observations (researcher's or others'), storytelling, documents such as hospital records, pictures, and video recordings (Moen, 2006).

The primary method of data collection within this research was the elicited oral accounts or stories of research participants and their interview transcripts. A researcher uses interviews to delve beneath generalizations of society to elicit the stories and

knowledge of “ordinary people”. This type of information gathering according to Fraser (2004) is particularly important for “ordinary women who are liable to be omitted from many research projects (p. 184). As well, by entering into dialogue, it is possible to challenge official statements or established theories and create new theories that are more appropriate or reverberate more with peoples’ current lives.

This research then engaged participants in several open-ended semi-structured questions (see Appendix G). As described by Tutty, Rothery, and Grinnell (1996), the semi-structured interview is situated between the structured and unstructured types of interviewing and is sometimes called a “guided interview”. According to the authors, “semi-structured interviews are particularly appropriate when you want to compare information between and among people while at the same time you wish to more fully understand each person’s experience” (p. 56). By engaging directly with the participants, they were invited and encouraged to tell their stories. But at the same time, the semi-structured nature of questions and some supplementary probing questions, to elicit more detail, may have helped to avoid the interview being completely controlled by the participant (Clandinin & Connelly, 2000). I utilized the interview guideline questions because it was important to the researcher and the research that each interviewee be asked similar questions and that stories obtained at least touch on as many of the questions as possible so there was a way to discuss and compare the range in participants’ experiences. Such questions as: “Tell me about a day in your life of taking care of your spouse (common law or life partner)”, offered a focus but no preconceived agenda for information. Subsequent probing questions were asked

for clarification. These questions included: "How did you take care of yourself?" "What types of supports were made available to you (if any)?" Supports may include friends, other family members, church groups, or other service organizations (Lions or the Legion for example). "Did you access any supportive resources for yourself?" For example respite, home care, and/or social work. "Tell me about your experience of the resources." Therefore, much of this study relied on individual interviews with women caregivers.

I conducted a single intense interview with each participant that lasted between one and two and one half hours between September 2007 and December 2007. Interviews were conducted at a location chosen by the participant and agreed to by the researcher. These locations included participants' homes with four participants and the palliative care office with one participant. From my perspective, the interviews went very smoothly. Each woman was very gracious with the information she shared and I did my best to supply a comfortable environment with space to tell their story however they needed to and add as much information as was important for them to feel complete. Everyone willingly answered my questions and a couple of participants came prepared with notes they had taken or articles, about their situation, that had appeared in local newspapers. In the end, each woman spoke of how relaxed and supported they felt through the interview and was appreciative for the opportunity to be part of the process.

These interviews were digitally recorded and transcribed for data analysis. The option of a second interview was offered to each participant at the conclusion of the first with the explanation that if the participant felt there was more she wanted to say or add, she could contact me either by phone or email and a subsequent interview or information exchange would occur either by phone or in person. Also a request for a subsequent interview would have been sought in the event further clarification or other information was needed. However, no woman contacted me for a second interview and I did not feel the need to gather more information or seek clarification with anyone.

Because of the nature and sensitivity of the topic of study, it was possible during the course of an interview for emotions to surface and for participants to need extra support after the interview. During the interview and immediately after, I was available to debrief with the participant to ensure they were alright. For three participants, this became important as emotions surfaced that they said they did not expect to be present or to the intensity they were felt. On one occasion, we took a break in the middle of the interview to give the participant a chance to debrief and regroup before proceeding with the interview because she had become overly distraught. At the conclusion of the interview process, all women felt they were in a good space and would not need extra support. However, beyond my immediate support and in case further support was needed, the consent form contained the toll free number for Klinik Community Health Centre's 24 hour crisis line which I had highlighted on each form and specifically pointed out, and I provided pamphlets of Health Region counselling resources available in a participant's area (see Appendix H) in the event they wished to seek further support in

their area. As I automatically supplied these supplementary resources, I am not aware if any woman needed or took advantage of these supports.

Using contact information gained from the first interview, I will contact participants, by October 2008, with the overall summary of the findings to ensure they receive a summary incorporating and reflecting what their experience was. This ensures the women have the opportunity to see the final product that they had a crucial part in creating. As well, this was discussed as part of the incentive for participating in the study.

### ***Data Management and Analysis***

Narrative analysis is not prescriptive by nature, therefore, how to utilize data management and analysis is much more open to the discretion of the researcher. However, narrative work does require the researcher to continually use self-awareness and self-discipline when examining the text against interpretations and vice versa (Lieblich et al., 1998). For this study, two authors Lieblich et al. (1998) and Fraser (2004) offered methods of analysis, that when drawn from, allowed me to create my own structure and which I drew from in order to create the richest results possible.

Fraser (2004) offers a line by line approach to data that she says is used most often in small scale research because the analysis is extremely labour intensive and it produces "fine grained data". Her approach is to lay out a series of "overlapping and un-sequential phases" (p. 186) for data analysis. I drew particularly from here stages and

utilized them for sorting through the data. Although Fraser (2004) says her approach is un-sequential, I found that when I made a more linear path with her phases I was able to wade through the analysis material and come to valuable conclusions. Fraser's work could best be described as my template working through the data.

Lieblich et al. (1998) on the other hand visualizes narrative analysis as a matrix of two main but independent dimensions that intersect creating four modes of reading a narrative. These include: Holistic-content; Categorical-content; Holistic-form; and Categorical-form. Although an entire narrative reads from most of these in the process, I found the Categorical-content dimension the most appropriate to use within this study. On the continuum of holistic to categorical analysis, I leaned more to the categorical pole. The Holistic extreme of reading the data seemed too broad for this study. I felt that I would not be able to do the data justice utilizing a holistic approach because I was looking at a very specific and relatively brief period of time within the participant's life and the holistic approach seems to look more broadly at the narrative and data; whereas I felt more comfortable with the data toward the categorical pole. According to Lieblich et al. (1998) "the categorical approach may be adopted when the researcher is primarily interested in a problem or a phenomenon shared by a group of people" (p. 12) and this was consistent with what my study was looking at.

I also chose not to focus on the "form" extreme of the content-form dimension. This decision was based in part on my decision to look through the more obvious content of the narratives rather than focusing on timelines and structures for instance.

The content extreme of this dimension seemed slightly more concrete for use with this study and appealed to my desire to look more at the concrete than the abstract of the narrative. As Lieblich et al. (1998) says “the categorical-content approach is more familiar as ‘content analysis.’ Categories of the studied topic are defined, and separate utterances of the text are extracted, classified, and gathered into these categories/groups” (p. 13).

Shortly after each interview, my first step was to listen to the entire interview on the tape to ensure it was all audible. For any interview where there was significant background noise that muffled the interview or if a lot of speaking was softer, I wanted to ensure I transcribed those relatively quickly so I would not risk losing significant sections. This first listen was also a chance for me to get a general ‘sense’ of the interview including the flow. All participants appeared to be comfortable enough to be open with their emotions as they were experiencing them. On a number of occasions such things as sadness, anger, and joy were expressed throughout the interviews. I was listening for significant and obvious pieces of information that came through either in the telling of a story or when the participant became emotional. Preliminary notes were made that included a couple of obvious themes: communication and team work and the importance of family and friends for support. Also during this listen, I made sure to note the time on the digital recorder when I recalled specific and perhaps important body language movements. For example, one woman when she spoke of sleeping in a chair by her husband became very fidgety in her seat as if she was feeling that

uncomfortableness at that moment. This according to Fraser (2004) may help to articulate better how and why a conversation unfolded as it did.

After I listened to the tape the first time, I put it aside for a week or so and then re-listened to it again. This time, my listening was strictly focused on how I as a researcher was responding to the information I was hearing. I reflected on my responses to the women as they spoke, when I asked questions, sought clarification, and generally how I was feeling. As well, I reflected on how I was feeling at the present time as I listened to the stories unfold. The multiple listening times were important because as Lieblich et al. (1998) suggests

Working with narrative material requires dialogical listening to three voices (at least): the voice of the narrator, as represented by the tape or the text; the theoretical framework, which provides the concepts and tools for interpretation; and a reflexive monitoring of the act of reading and interpretation, that is, self-awareness of the decision process of drawing conclusions from the material (p. 10).

I found that I certainly empathized with the women as they told their stories and remained engaged throughout each interview. I recalled having moments of being very touched by something a woman said like when one spoke of her grandson taking a tour of the house after being told his grandfather had died and I reflected how similar that was to my experience. I had moments of feeling sadness at the loss of life and excitement and joy at the determination and commitment to live life the way they (participants and spouses) wanted to. I also found a couple times in my listening to the

tape that my curiosity about a particular comment or story was peaked and I wondered what happened beyond the story. For example, one woman had a very difficult time with a doctor and I wondered if the participant ever got an apology or found a way to tell the doctor her frustration. However, because it was outside the scope of this research, I chose not to pursue answers to those curiosities. This step became part of my reflexive monitoring of myself as I engaged with the material.

My second step was to transcribe the interviews. This was an important phase as it gave a concrete record of the interviews and meant I did not have to rely simply on memory. Using a dictation program (Dragon Naturally Speaking 9), I was able to re-dictate each interview into the computer and then go back over it listening to the tape and reading for accuracy. Once the preliminary training of the program was completed, it proved to have good accuracy with dictation. Line numbers were added so an audit trail could be established as suggested by Fraser (2004).

Although it was a time consuming process, each interview took about 6 hours to transcribe, I saved many hours of typing time by utilizing a dictation program. It was important and recommended that as the interviewer; I perform this task because I could more accurately reflect the story as it was told. I added such things as silences, pauses, emotions, and significant body language (as per my notes from the previous step), as they may have been significant within the story. Transcribing the stories myself allowed me the chance to hear the narrative a third time paying attention to yet a different aspect. Also transcribing data myself, eliminated the need to ensure confidentiality was

maintained by outside transcribers or concern myself with briefing and debriefing transcribers who may have found material difficult to read due to reactions (Fraser, 2004).

The third step was to interpret transcripts. This stage had a number of pieces to it. First, as was suggested by Lieblich et al. (1998), I chose my subtexts based on the research questions I had asked the participants. Files for seven separate subtexts were created including: advice for those starting out, care of self, challenges of caring, information for policy makers, learnings, positives and rewards of caring, and supports. I then made notes on each transcript identifying themes that were emerging and connected them to these subtexts. Although I looked for and was prepared to explore inconsistencies within any transcript as was suggested by Lieblich et al. (1998), I did not find any contradictions within the transcripts.

I then moved information from the transcripts into the appropriate subtext files. Large blocks of information were easy to move as each woman seemed to remain focused on the question asked and so I was not in the position of having to wade very often through intersecting threads of material. Smaller sections were gleaned from their general telling of their story as well. As sections of transcripts were added to these files, the line numbers from the transcripts were recorded beside the section to ensure an accurate audit trail as indicated by Fraser (2004). By the end of this process I had gathered all the information from the individual transcripts into a common area and was able to read all information for each subtext from each participant's story.

Once all the information had been reduced to the seven files, I read through and analyzed each subtext file, looking for themes that crossed over into other areas. For example, the theme of communication became prominent in a number of subtext files. Notes were made on each subtext file with these emerging themes and once again, these new themes were brought together to be assigned their category. This analysis produced three main categories: self care, communication, and support.

Although Lieblich et al. (1998) suggests that the next step is to draw conclusions from these results, I found it necessary to refine my categories one step further to create a number of subcategories. This refining allowed me to more accurately and fully create a picture of the content expressed by the participants. It also gave me the chance to identify the differences that these women articulated in a number of areas. For example, some women had very positive experiences with formal supports, while others had negative experiences. These differences needed to be documented and conclusions needed to reflect both understandings.

Fraser's (2004) step four was to link the personal with the political. Although in theory I really liked this idea of looking at the social conventions of women and how their language creates the framework for their stories, I found this to be difficult to do. When I really got to looking at the stories, this piece did not seem fit to with the overall goal of the research. Therefore I chose not to pursue this stage in relation to the analysis. However, I did utilize this step as a way to ask myself some important questions. Fraser suggests the researcher ask themselves "Have you clearly distinguished

participants' accounts from your own [as the researcher]? Or are their [participants] accounts becoming too subsumed by your analysis?" (p. 193). I utilized these questions as more self reflection. I realized in my attempt to create a strong feminist piece to the analysis I was actually creating my own agenda rather than keeping to the women's stories. So although I wanted to create the personal and political link, it was not in line with the flow of the research.

My final step was to pull all the threads together and write the academic narrative utilizing the themes and sub-themes I had discovered. This step took about four months as I wrote a section and then went back to the transcripts to ensure the analysis of the theme was representative of each woman's experience and story. This continual reference back to the original transcript is suggested by Fraser (2004) as a way to ensure the narratives being created corresponds to the stories told. She also suggests this process continue until the final presentation of the paper.

This final piece also had an element of self reflection. Fraser (2004) says

We also know that humility is an important trait for us to demonstrate if we are to 'stay true' to the philosophy of the method. Yet, humility need not be an enemy of conviction. The two may coexist if one accepts that, '[A] narrative is never concluded, it is always subject to reconstruction and reinterpretation' (p. 196).

This quotation became a very important part of my final process as a researcher. To continue to remember that the narrative is never concluded and there is not the perfect

answer was crucial to me being able to humble myself and complete my analysis. I found myself able to “let the analysis go” and trust that the work I had done was reflective and representative of the women’s stories and that I had done justice to the experiences of the participants.

Once the final presentation of the paper is concluded, a summary of the findings will be generated and provided (by October 2008) to each participant by way of email or mail determined by the participant’s preference. As well, summaries of the findings will be made available to women who request them and the Regional Health Authorities who participated in recruitment. The University of Manitoba receives a copy of the completed thesis. Proposals to disseminate research results at such conferences as the Hospice and Palliative Care Conference will be submitted.

### ***Ethical Considerations***

Besides the general ethical considerations already taken into account throughout this study, nothing unexpected was encountered with respect to ethics.

However, because of the nature of qualitative research and interviewing, ethical concerns and any issues of confidentiality were given serious consideration for this study. Confidentiality of the participants was given high priority particularly in light of the fact that interviewees were from rural areas and the possibility for others in the community recognizing their stories was possible. Patton (2003; 2002) points to an “Ethical Issues Checklist” used as a framework to assist the researcher to address any

areas of concern prior to the beginning of the research. Within this research, I identified informed consent, confidentiality, data access, associated risks and benefits, and reciprocity as concerns to be addressed.

The standard University of Manitoba research ethics review process was followed (see Appendix I). Forms for informed consent were completed before the beginning of the interview (see Appendix J). Each woman had the opportunity to read the presented form and ask any questions necessary to understand it. In one instance the participant asked me to read and explain the form as she felt she was a slow reader and unable to process fully and quickly its meaning.

The consent form outlined the study and its procedures as it involved participants; had contact information about the researcher and advisor; assurance that participation was voluntary and withdrawal could occur at any time without penalty; assurance of confidentiality and limitations of such; and any risks or benefits associated with the study. This was in line with the basic elements of informed consent as identified by Padgett (1998).

At the end of reading through the consent form, no questions were asked or clarifications sought by any participant and no concerns were raised about the study. Therefore all participants signed two copies of the consent form indicating an understanding of requirements and a willingness to engage in the process. One form was then given to the participant for their files and one was retained by me for my files. As well participation needed to remain informed throughout the research process and

participants were encouraged to seek clarification or ask for new information throughout participation in the research.

Each participant's documented consent to participate remains confidential. It is stored in a locked filing cabinet in the researcher's study. The data, both digital voice recordings and transcripts, are stored separately from the consent form in another locked file cabinet to ensure confidentiality. Participants' interviews contain no names or other personal identifiers. After graduation from the MSW program, paper transcripts, consent forms, and any other identifying information will be shredded and the interviews will be erased from the digital recorder and deleted from computer memory and other storage devices.

The risk to participants about being identified due to their involvement in this research by other community members was addressed by ensuring them confidentiality. Every effort was made to ensure the identity of participants was not revealed. I advised participants I would be excluding any identifying information in my thesis report and other dissemination in order to protect their identity. The possibility, however, does exist that despite my efforts, they may be identified because the areas where the participants reside are small and so even the most subtle detail could give their identity away. I discussed this reality with participants as a potential risk and stated it in the consent form. None of the women articulated any concern with this issue. However when writing this paper, I chose not to identify individual participants with pseudonyms

but rather combine them in order to further protect identity because with only five participants it is much easier to connect quotes and expressions to determine identity.

Also stated within the consent form were other circumstances where I needed to show identifying information to another person. For example, I was required to show or discuss information that may identify participants to my faculty advisor who needed to be sure I had done the research analysis appropriately and offer me support. I did not however, need to show or tell about any participant's information to authorities as there were no threats of violence, commission of crimes or suspected child abuse.

An incentive for participating was also discussed. Each participant will receive a summary of the findings of the study by October 2008, and if desired may also receive the complete study report, in appreciation for their contribution to the research. Each participant asked to receive a copy of the summary of findings and provided either an email address or physical address.

## Chapter IV: Findings

This chapter reflects the information garnered from the interviews with five women from three rural regional health authorities. It begins with the demographics of these women and looks at how representative some aspects are to the general population. The next section formulates an analysis of their stories with respect to their experiences, followed by what participants indicate as their needs for providing care. The chapter concludes with recommendations of the women to improve service to meet their needs for caring.

### *Characteristics and Demographics of the Women Interviewed*

The call for participants produced a total of six women interested in being interviewed. However, of those only five met the criteria I was working with and as a result, the sixth woman was excluded because her spouse had died from something other than cancer and as I had five others fitting that category, I chose not to pursue an interview with her. Therefore all the results are based on intensive interviews with five women.

Table 1 on the following page offers some characteristic and demographic information with respect to the participants in this study.

Table 1: Characteristics and demographics of participants

<b>Age at time of spouse's death</b>	48 – 69 years (mean 61 years)
<b>Age of Spouse at death</b>	49 – 72 years (mean 66 years)
<b>Length of Time together</b>	10 – 50 years (mean 32.4 years)
<b>Relationship Type</b>	All married – heterosexual
<b>Ethnicity</b>	Ukrainian, Icelandic, Caucasian
<b>Employment</b>	Part-time, semi-retired, volunteer, homemaker, full-time
<b>Distance living from major centre (Winnipeg)</b>	35.2 km – 158 km (mean 93.2 km)
<b>Issues regarding woman's health while caregiving</b>	High blood pressure, increase anxiety, acid reflux (heartburn), pre-diabetes, high cholesterol, tiredness, none
<b>Illness duration of spouse</b>	
- <b>From first diagnosis</b>	4 months – 9 years (mean 4.9 years)
- <b>From terminal stage</b>	2 months – 2.5 years (mean 10.4 months)
<b>Type(s) of cancer dealing with</b>	Liver, lung, melanoma, non-Hodgkin lymphoma

The participants ranged in age from 48 years to 69 years, with an average age of 61 years at the time of their spouse's death. At the same time, the women reported their partners range in age from 49 years to 72 years, with an average age of 66 years.

All of the participants indicated they had been in a heterosexual married relationship with their partner for a significant period of time; the average length being 32.4 years and the span being 10 years to 50 years.

When asked about their ethnicity, three identified with being Caucasian while one identified as Ukrainian and one identified as Icelandic. The women's partners' ethnicities came out the same way, with the exception of two. For these there was some Métis and some Belgian included.

The women's employment was significant to look at as the issue of financial support through the government came into play. With five women participating, there were five different responses to employment. These included: part-time, semi-retired, volunteer, homemaker, and full time. This meant that only the one working full time would have qualified for support from the government through the compassionate care benefit and this woman actually chose to continue working through this time.

Only two of the women said they had other family members or friends present in the house on a daily basis. Of those two, one had younger children living in the home and the other one had grown children who would return in the evenings after they finished working. At the same time, four of the five women pointed to having family members living close to them in their communities.

Women were also asked if they or their spouse had affiliations with community groups prior to the illness. Most women were able to identify multiple connections with community groups. These included: the Kinsmen, Heritage Committees, Kiwanis, golf club, senior's clubs, pre-retirement work supports, cancer resource, church groups, cemetery board, and conservation district. Further, with the exception of the spouse slowing or ceasing his involvement upon his illness, most said their connections continued and they garnered support from these places.

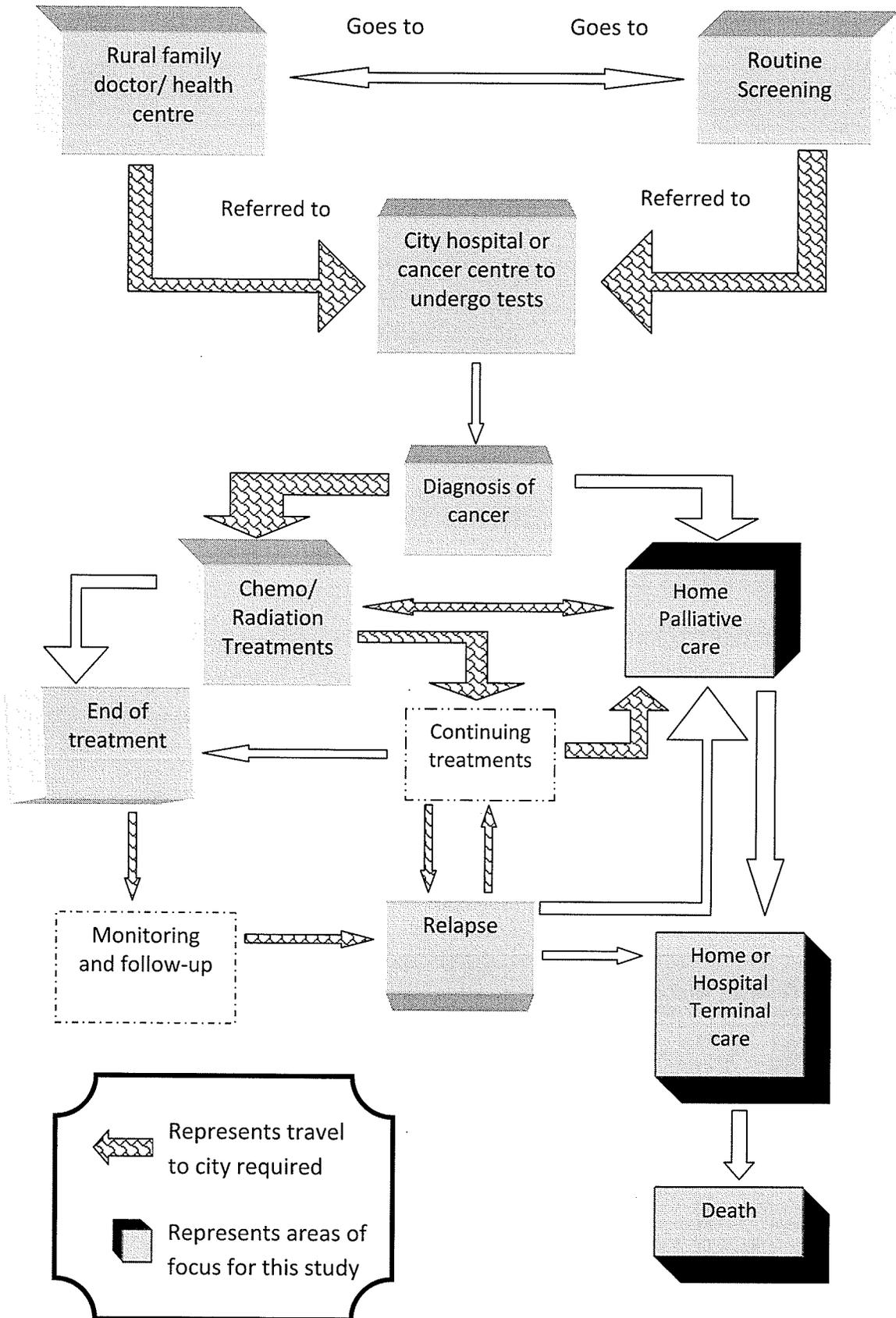
Although these women did offer primary care to their spouses at home, their health during this time was also important to take into consideration. Only one woman said she had no issues to report with respect to her own health during this time. All

other women reported at least one significant issue ranging from tiredness to more serious issues such as high blood pressure, increased anxiety, acid reflux (heartburn), pre-diabetes, and high cholesterol.

***Cancer: Type, Duration, and Process***

Finally, women were asked about the type(s) of cancer their partners were diagnosed with and the duration of the illness both from first diagnosis and from terminal stage. Types of cancers reported were liver, lung, melanoma, and non-Hodgkin lymphoma (see Appendix K). The duration of each illness varied substantially from 4 months to 9 years with an average length of 4.9 years. The variation in the length of time from being told the spouse's cancer was at the terminal stage ranged from 2 months to 2.5 years, with a mean of 10.4 months. Figure 3 shows the pathway through the cancer process and offers a visual map of the steps taken during this time. Note that the researcher's areas of interest in this study are represented in the highlighted boxes.

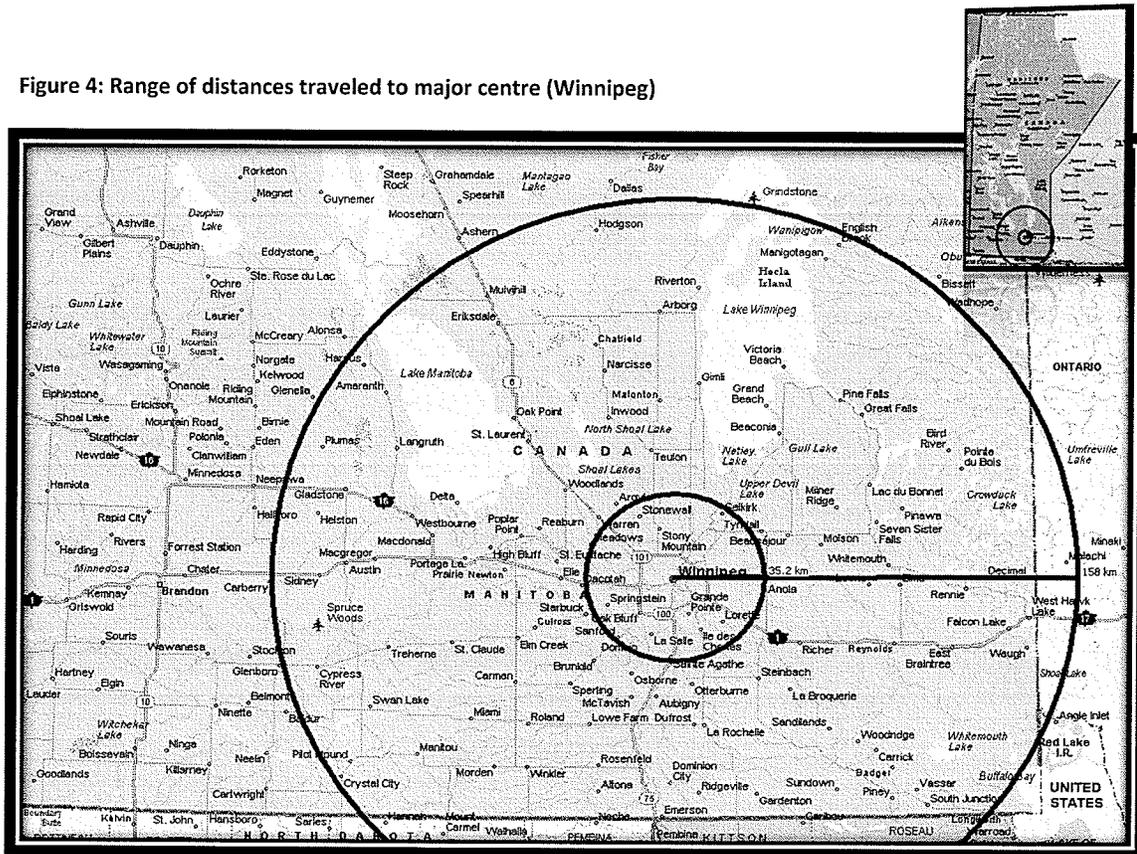
Figure 3: Pathway through the cancer process for participants and spouses



**Distance from Major Centre (Winnipeg)**

Women interviewed originated from three rural health regions. Although all women indicated they had access to doctors and hospitals within a reasonable distance to their home (usually in the community) and were often under the care of those physicians, they each indicated that there were times when they had to travel to a major centre (Winnipeg) to see specialists such as oncologists or to have other tests and such done. On the average, they travelled a distance of 93.2 km each way in order to attend those appointments. Figure 4 shows a map offering a visual description of the rural area covered. The area between the two circles represents the area the participants resided in. Note that only areas within Manitoba are included.

Figure 4: Range of distances traveled to major centre (Winnipeg)



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### ***Place of Death***

Although all participants in this study offered palliative care to their partners in their home for a period of time, not all spouses chose to or were necessarily able to die in their homes. Of the five women interviewed, two participated in planned home deaths, while three women's spouses were admitted to hospital for a short period of time prior to death and subsequently died in hospital. This, according to Statistics Canada (2007), is a fairly consistent trend in hospital and non-hospital deaths in the 2000s right across Canada. What is not available is a complete breakdown of non-hospital deaths (as these include deaths in long term care facilities including nursing homes and short-term care facilities including nursing stations) so a true percentage of home deaths is not known. Figure 4 is a graph showing the percentage of hospital, non-hospital, and unknown places of death for the population of Canada from 2001 through 2005. I have compared the percentages from each year, in each of the three categories, with the percentages of where this research study's participant's spouses died. Figure 5 narrows the location to Manitoba looking at where people have died within this province. I have again set the percentages of each of the three categories in each year from 2001 through 2005 next to this study's participant's spouses' location of death. What can be seen is that proportionally, the five women I interviewed statistically is representative of the trends in Canada and more locally in Manitoba.

Figure 5: Place of death in Canada from 2001-2005 compared with spouses (in %)

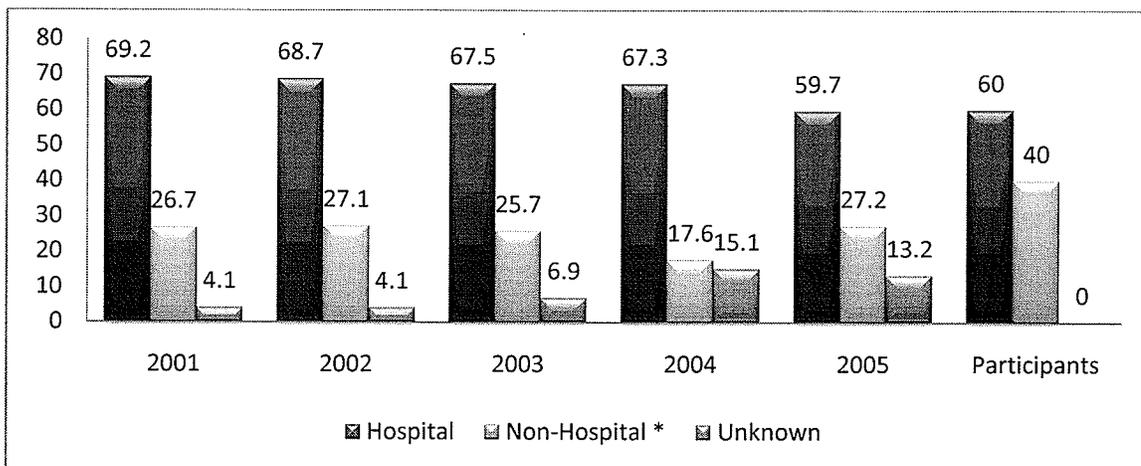
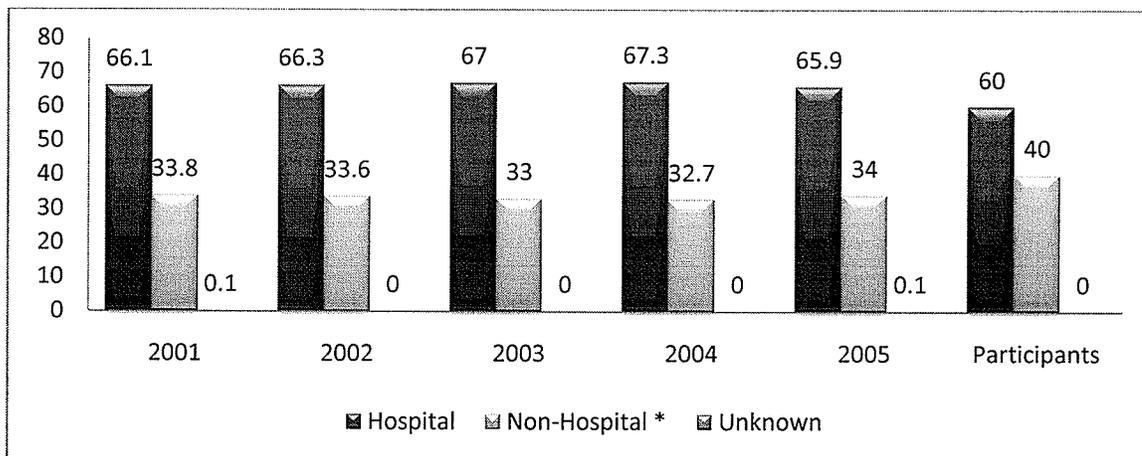


Figure 6: Place of death in Manitoba from 2001-2005 compared with spouses (in %)



\* Non-hospital includes deaths that occurred in private homes, in health care institutions such as nursing homes and other long-term care facilities, nursing stations and other short-term care facilities and other health care facilities not licensed to operate as hospitals by provincial, territorial or federal governments and at other specified sites.

(Statistics Canada CANSIM database, Table 102-0509 - *Deaths in hospital and elsewhere, Canada, provinces and territories, annual*, <http://cansim2.statcan.ca>, Retrieved January 14, 2008)

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### ***Experiences of Home Palliative Care***

It was important for the purpose of this project to understand the experiences women had when it came to caring for their spouse at home. I wanted to understand what the positive aspects were as well as the challenges to taking on this responsibility. By doing this I would be better able to understand what they said their needs and wants were.

#### ***Positive Aspects of Caregiving***

The most important and positive aspect women mentioned were being able to provide care in their own homes with their own things. Each of them in their own way described how much easier it was to be at home while caregiving. By not having to go back and forth to a hospital or hospice, women felt they had more quality time with their spouse and that others also got more time and space to visit.

One of the positive things is that you're in your own home, you can come and go, and you can sit. You know I have a little TV and I have headphones so when he was sleeping I would sit beside the bed, hold his hand, and watch TV. The kids could come whenever they wanted. I think it was just as comfortable for him, if not more, plus it was much more comfortable for me because I know I didn't have to do everything for him.

[Friends] would come and visit him and [the pastor would] give communion at home or whatever. A lot of people called to see how things were.

I was able to be in my own home, it was nice, we didn't have to be institutionalized or anything like that, dealing with nurses or variables, to be free within your own home.

Here if there was a movie that someone wanted to watch with him or you, you still can be a part of their life as it was before so to speak. You can do whatever you want to, you can say whatever you want to say, and stay however long you want to stay, you know, sort of thing.

Also, women said that by being at home, they were better able to provide the comforts their partners needed. One woman specifically talked about comforts as having an outlet to continue with some daily routines like going to town for the mail, and other small outings like that. By doing some of these "normal" activities, she indicated the disease was not seen as taking over their lives. With respect to comforts women reported the following:

It's very gratifying when a person is suffering hard and if you can give that person time and effort it's very rewarding. To watch a person be in such pain ... My focus was to make him feel good.

The most positive thing was having been able to have him being at home where he wanted to be and just having him comfortable as much as could be.

I was able to support him and actually be with him all the time towards the end. To know that he had someone there with him that really cared and that was by his side until that day he died.

### ***Challenging Aspects of Caregiving***

Although women said that the positive aspects of caregiving outweighed the challenges and all said if faced with doing this again they would, there were definite challenges along the way. Challenges seemed to come from different places. Some challenges were personal in nature, a feeling of inadequacy about not knowing what to do or being able to make it better or not being able to get enough self care.

I guess the challenge was to make sure I was doing the right thing. I felt so inadequate when I was around the chemotherapy and things like that.

What was very frustrating for me was that I couldn't make it better. I couldn't do that. The doctors couldn't, I couldn't, and I wanted to make it better.

What was challenging was no sleep. I found it hard to sit for months and sleep in this chair day in and day out.

Other challenges were practical in nature. A couple of the participants spoke about how toward the end it got difficult to physically do all the things necessary for their partner. As a spouse retained fluid he would get heavier and so lifting became difficult. For another as a spouse became weaker, getting him dressed, helping him get dressed or even go to the washroom became tougher.

Many challenges were also systemic in nature. Many women talked about the challenges they felt when dealing with the healthcare system, from the hospitals to the doctors, nurses and other professionals. Some had difficulty getting adequate

information from doctors, while others felt at times they had to take responsibility for ensuring supplies were available at the local hospital or adequate supplies of oxygen were available for prolonged stays in the city due to tests or surgeries.

The most challenging aspects are dealing with, at that time the medical system. One of the biggest issues was dealing with nurses that didn't appear to have an affinity for what was going on, not understand the struggle that you are going through trying to look after your loved one.

These challenges created the basis for women's understanding and reflecting on what they needed and wanted when it came to caring for their spouse in the palliative stage of their cancer.

### ***What do Carers Want and Need?***

Participants, when asked to reflect on what they wanted or needed during their time of caregiving, in the beginning had difficulty answering this question. It was clear how focused on and present for their spouses they each were. Each woman was able, in great detail, to talk about and relay the story of her husband's illness, touching on almost all aspects in the pathway through the cancer process, including what his wants and needs were and how and what services would have provided better care during his illness and to his death. However, when it came to focusing on what the caregiver participant needed or wanted, a lot more thought and reflection was needed before they were able to articulate their own needs. As one participant said, "I was basically the caregiver and so it was like being at work 24 hours a day". Perhaps this played a part

in the difficulty of focusing on their self care as usually one does not focus on oneself when they are working.

However, by the end of each interview, participants were able to articulate many things as either having been helpful or that would have been helpful during this time. Through the analysis process, three main themes and some subthemes emerged as common elements necessary for a woman to feel successful and healthy as she offered palliative care to her spouse. These themes are: communication with subthemes of team work and access to accurate, timely information; support systems, both formal and informal; and self care. A fourth theme emerging combined advocacy and emotional and practical support and was seen as roles a social worker may play. Each of these is further discussed below.

### ***Communication***

Communication overwhelmingly was the most definitive theme for all the women interviewed. Communication was seen as important with both informal and formal supports. Communication among family and friends was crucial. As one woman put it, she was not a rural woman who did not communicate. For those who were able to communicate clearly, there was a feeling of connectedness, while for those who did not have that with family or friends; there was a sense of being alone.

When it came to formal supports, throughout our discussions, women continued to come back to how important a clear flow of information from health professionals to

themselves and their partners, and from them to the professionals was for the successful care of their husbands. Those women who talked about feeling alone in the process of caregiving, commented about either being offered no information, inconsistent information, was spoken to in a condescending manner or was excluded from various conversations that took place. Few of the women spoke of having a positive experience. However of those that did, consistent and accurate information and being part of the team and decision making certainly contributed to such feelings. Being considered part of the caregiving team was important and yet was often not experienced by the women.

He [the rural doctor] pulled me aside and he said 'You need to know his time is short. He may make a year, he may not'. And I, I was so grateful for that because he's the only one who told me that and it gave the guidelines. The other ones [the city doctors] said nothing. They said, 'Oh well he'll be fine'. He couldn't be fine, his body was totally fried.

Women then described successful communication as falling into two important categories; team work and access to accurate, timely information.

### ***Team Work***

Each woman talked in varying degrees about the desire to be considered a full participant of the team caring for her spouse. Some women were very successful in being considered team members. Of those women who described their experience as positive, all were involved with the healthcare team in some form prior to their partner

becoming ill. As one woman said, this may have contributed to the success of the team as she already knew the doctors and nurses who were working with her husband and she knew what questions to ask, what information to pass along and how to pass it along.

Anything we wanted was provided for us. The Health Centre offered their services but often I didn't know what to ask for because I didn't know what was ahead. But once I spotted a problem all we had to do was phone.

I found that if we were in need at all, all we had to do was ask and there were times I didn't know what to ask for until we really needed it. But it was there.

On the other hand some women articulated difficulty in being recognized for their knowledge and skill. For example, one woman spoke of knowing something was not right with her partner upon returning from a time away from him. However, even when she explained his symptoms, the doctor told her there was nothing wrong, it was simply his treatments. But later when further tests were run, in actuality there was a fairly significant problem. This woman said she felt quite disrespected and wondered why her experience had not been considered more because after all she lived with him and knew him well. A second woman with a similar experience said

I phoned up and said I would like to see a doctor so they said yes come in and I was crying and said something was wrong with this man. 'Ooooh' and these were the head guy of radiology and the head of cancer care. 'There's nothing wrong with him he's just recovering from the treatment'

and I said, 'I'm imploring you, begging you there's something wrong beyond that'. 'Well, we don't see anything wrong with him'. So they called him in and there was actually two of them and I said, 'There's something wrong beyond his treatment. Would you please check'. But they said, 'There's nothing wrong'. And crying already I really pushed it. So when you start to cry, they start doing something. And there was one doctor and he said, 'Listen to yourself', and I said, 'No listen to me there is something wrong'. So to shut me up they tested him and discovered he had such a massive silent heart attack he only had 5% function of his heart left.

In both these circumstances the women felt they were right in the situation but the health care professionals involved chose not to take seriously their concerns. This led to a negative experience with some health care professionals and ultimately left a bad feeling for the women. From that point forward, neither woman had much that was positive to say about the team experience in palliative care and felt quite alienated and disrespected. Further it made cooperating with some of the professionals difficult and trust was at a minimum.

### ***Access to Accurate, Timely Information***

There were only a couple of ways women talked about gaining information about their spouse's cancer or other information necessary in the caregiving process. One common way was through the internet. Many women spoke of surfing various web pages looking for information about particular cancers and by reading up on what was going on and were able to take questions to the doctors in order to gain answers

specific to their circumstances. Women also indicated that by having access to the internet, they were able to do something “productive” in between doctors’ appointments and did not have to rely solely on what the doctors were saying. For example, one woman said

Like one of the things that we had looked up, well my daughter had looked up and found out about asbestos tumours and my husband had worked with asbestos and I had never even thought of that but the doctor said, ‘Yes that's one thing we had actually thought of’.

In this instance the woman said her family was able to be assured that all possible causes were being taken into consideration and that the reason for the cancer may be explainable and a treatment relative to the situation could be considered.

Another woman said she looked up a whole lot of things on the internet to find any information on the particular type of cancer her husband had. By doing this, she learned that not much had changed in ten or so years as the same chemotherapies were being used even though the success rate was not very good. Therefore, although the internet was seen as a mostly useful source to access and gain information, it was important for women to be cautious about what sites they were getting the information from and to check it out with the doctors. For the most part, doctors encouraged this kind of research, although a doctor, according to one woman, whose family asked many questions, did comment about the fact that someone must have been on the internet perhaps a little much. It was felt this comment was not to discourage the family, but

rather to caution them. For those who were not internet savvy, other ways of accessing information included books, articles, and resources from healthcare centres.

A couple of women spoke of using observation as a way of gaining information. Observations were especially made while partners were receiving chemotherapy at the Cancer Care Centres.

I spent so much time at the Cancer Care and waiting that I was studying everything that happened and figured out that we were all getting the same chemo and every time we changed we were all getting the same one again. They were all turning gray the same time, they were all losing hair the same time, nurses had the same conversations with patients, there was a lot of observations.

Besides doing research and gaining information on their own, women indicated they wanted and needed accurate information from the health care professionals such as doctors and nurses in a way that was accurate and not cushioned in promises that could not be given or kept. One woman spoke of having gone through chemotherapy treatments with her husband and the doctor said everything would be fine in five years; that if they made it to the five year mark, he would be cured. Well according to her, they did make that five years, but shortly after the cancer returned and she felt the promise he had made had been broken. In her words "No dates should ever be promised on life because it's not true". A second example of a promise made by a doctor that went unfulfilled came after a spouse had a computed tomography (CAT scan) and was told he had no cancer in his body, it was contained. In this instance, the doctor assured the

family that it would be no big deal to get rid of the existing cancer and he would be cured.

So we're all happy. So we'll have you start chemotherapy real soon and we'll get this done real quick. So we're waiting, waiting, waiting and three months go by, three months and I say you know I'm phoning them because I said we shouldn't be waiting for so long.

In this instance, subsequent tests discovered that the cancer had actually spread and he was not cured. The woman indicated she felt her hopes had been raised only to be dashed and that this was not fair for the doctor to do. This example also lends itself to yet another issue that women spoke about, timely manner. When it came to getting information about referrals or timing for chemotherapy or radiation treatments, women indicated they were often left feeling in the dark. For some, months would go by before they would choose to make calls themselves to find out about subsequent appointments. This lack of smooth flow contributed to the stress level women felt which added to the already difficult process of looking after their loved ones' care. Some indicated that they felt like the care coordinator because they had to make sure everything was in place, appointments were made, referrals were received, and items necessary for care were where they were supposed to be.

For the women, overall communication was important and very complex. It involved not only verbal communication but also the process of learning and the process of executing all those things that were necessary in a team process of taking care of their loved one. For some they did not feel part of the team in one way but were

expected to be the team leader in others. This inconsistency sometimes added to the stress levels of the women.

### ***Support Systems***

Women spoke at length about their support systems while caregiving. Each woman was clear and appreciative that she did not work in isolation, but to some extent was surrounded by a circle of support. These supports were both formal and informal in nature and although the configuration of each woman's support system looked different, it often contained similar elements.

#### ***Formal Supports***

All women indicated they were heavily involved with the formal support services as they cared for their spouse. At the same time, all women indicated similar types of formal supports that were available to them. Each woman spoke of formal supports as including doctors, nurses, home care, palliative home care, ambulance services, and pharmacists. Only one woman indicated the Province of Manitoba's palliative care drug access program as a formal service. Further one woman indicated a mental health worker as a formal support but qualified it by saying if she had not been in contact with her prior, she would not have been involved in the caregiving process. Of these support services, all were primarily focused on their loved one and only secondarily focused on them.

**Doctors.** It did not take long into any interview for women to identify doctors as their first step into formal care and support. For a couple of women it began with their family doctor, while for others it was an unknown doctor perhaps from an emergency room. It also quickly became clear that for all women, there were many doctors or specialists that became a part of the caregiving team. However, only two women identified doctors as being a positive support during the process and found their involvement to be exceptionally good.

I would think during that last two weeks that particular doctor if he wasn't at our house at 8:00 a.m. he phoned. If he was there in the morning, he would phone at night and we found that over and above the call of duty. If it was a Sunday and he was on his way to the cottage, going by on his cell phone he would phone, "Do you want me to stop in"?

In both cases, the doctors who were seen as helpful were the rural community doctors. Perhaps this is because often the rural doctors live within the community, understand the culture of the community, or even know the family personally. In any case, the rural doctors often were seen as going above and beyond the call of duty to be available to their patients. This is not something that is seen within a city setting. Therefore, for the five women interviewed, the supportive doctor was an exception and not the rule. The number of city doctors these participants dealt with far outnumbered the rural ones. When it came to city doctors and specialists, more often women indicated a lack of communication between doctors, other team members, and hospital departments as creating a strain on the system and making it difficult to work with them.

*Nurses, home care, palliative home care.* Nurses were a second source of support women identified. Nurses played various roles from inpatient nursing to home care or palliative home care. Experiences of nursing care seemed to fall into two categories: inpatient nursing staff and home care and home palliative care nursing staff. Women's sense of support appeared to be mixed as well. When negatives were described in nursing care, it was always in the context of inpatient care in the hospital. Nurses in the hospital were often described as having a lack of understanding of what palliative care meant and what was needed on the part of both the woman and her spouse. On one occasion a woman indicated a particular nurse was "not very nice" and she felt her presence was more of a hindrance to care than a help. On another occasion, a participant indicated that a nurse was asked to clean up a loved one after he had an accident. The nurse said they would send someone in right away, but no one came. The woman continued to say she ended up cleaning him up herself and this upset her immensely.

On the other hand, nurses connected to home care and home palliative care programs were often seen as going above and beyond the call of duty. Participants found nurses and other workers in these areas to be incredibly supportive and very knowledgeable. They also were reported to have an increased ability and desire to listen to the concerns of the participants when it came to their husbands. Women had the following to say about home care, home palliative care, and nursing:

Home Care, the palliative Home Care here is absolutely fabulous. You couldn't ask for better. One phone call and somebody was here. He wasn't feeding properly, having problems in the bathroom, 'Yes you know what we're on our way'. Within a half hour they were here.

And that there is so much help available you just have to access it because there really is in this area. I think we're really lucky because we do have a lot of really good Home Care workers and from the Home Care worker to the nurses.

I said I was managing fine and I said I could look after him, but then they said, 'Well, we'll send a nurse down once a week,' and [name] came and there were two other ones and they would come and check to see if I was doing OK and I would say I was and then finally toward the end they said, 'No, we're not accepting that from you anymore you're getting help'. Especially once the oxygen machine came.

In homecare settings, ongoing relationships create connections that become trustful and meaningful. This is not always possible in acute care settings because the mandate is different and the length of time associated with a person is often shorter. Therefore it is understandable that more negative perceptions were associated with acute care nurses, while homecare nurses generated positive experiences. For example, in the above instance, because the nurse had an ongoing relationship with and had a good connection with the woman, she was able to assess the woman's ability to manage and help her balance it with her need for support in caring for her husband. The relationship

that had developed gave the nurse the opportunity to insist on bringing in extra support without demeaning the woman's ability to care.

***Ambulance and pharmacists.*** Women spoke of other formal supports such as ambulance services and pharmacists as integral to the success of their caregiving experience. On a couple of occasions, women indicated the ambulance service was called upon to do a variety of tasks including helping to lift a partner, transport to hospital, and sometimes just check up on them. One woman praised the ambulance service saying

I had to rely on the ambulance and they were so good. That's one thing I have to say is they were so good they always came in to see if I needed help to turn him or things like that and change the bed or to get him up in the chair and they helped me with that ... They came on every shift and they came in and came to see what I wanted and I called on them when we needed stuff in the hospital to give me help.

In many rural settings, professionals and formal support services do not practice within the narrow parameters of what they are paid to do. Often rather, these people also act in the capacity of informal supports. For example, the ambulance drivers who drop into this woman's home fulfilled the role of what friends or family may do but because they saw a need, they were there to fill it.

As well, the pharmacists were seen to be supportive when it came to discussing and ensuring medication was on hand for them when they needed it. One woman indicated that the medication her husband needed was only available at a particular

pharmacy in Winnipeg. After making the trip into the city to pick it up, the pharmacist offered to have it bussed out to her whenever she needed it. For her, this was an incredible help as it meant not having to leave her spouse for a long period of time to make the trip often, alone. For her, the pharmacist had the sensitivity to know the medication was important, but not having to make the trip to pick it up was just as important and he managed to find a solution to a potential issue.

Each of these formal supports contributed to the success of the caregiving team. For the most part, women found their team positive however each saw gaps that could have been improved upon to make a better experience. For some these gaps would be filled partially by informal supports, for others the gaps remained.

### ***Informal Supports***

During the interview process, it became increasingly clear that the informal supports that women had during the caregiving process was crucial for the success of their experience and was a definite need and want by all interviewed. Four of the women interviewed said they had a number of informal supports that they drew strength and comfort from. The one participant who indicated her informal supports were limited also claimed to have a much more difficult time coping with the daily aspects of caregiving. These supports fell within three distinct segments; family, friends, and community.

**Family.** A number of women indicated they had immediate family close enough to be present on a daily or every second day basis. These immediate family members included grown children, younger children still residing at home, grandchildren, siblings, and nieces. Those that did not permanently reside in the home were available to come into the home and take over some of the daily chores like cooking or cleaning, or simply sitting with the spouse to allow time for the woman to do some other things she felt needed to be accomplished like going to pick up medication, running errands, catching up with housework, or the odd time taking a little time for self care.

Our daughter, when she realized [name] wasn't going to church anymore, she'd come over Sunday morning and say, 'Get out of here, I'm going to be here' and so I could go to church and I could stay for coffee and not have to worry about getting home.

I got a lot of support from, I'm really close to my ex husband's side of the family. They gave me full support and I'm close to my mother's family and having the wonderful support of my dad even though he has no family here in Canada.

These supports were often "on call" for emergencies such as if the partner fell and the woman needed help getting him up, or having to go to the hospital for some reason. Many women also described these supports as being very involved in the cancer process. Some would go to doctor's appointments with the couple, others would drive the couple to treatments, and many were close by at the time of death and beyond death.

Extended family or family who resided further away from the home were also found to offer support although in different ways. When able, family appeared to come and stay with the couple for periods of time which allowed women a break from being the caregiver 24 hours a day. If a woman needed to run out and her husband was unable to be alone, she did not have to rely on home care to provide respite for that period. This sometimes made doing things simpler.

I think once or twice two people came out here, his mom and his dad. And his dad, he would phone often and they would come as often as they could, but it was hard because his mom [had health issues].

However, women also said, having other people in the house sometimes disrupted daily routines or simply offered extra energy to be around. Although women said they were happy family visited, understood the importance of their presence, and welcomed the company and help, it sometimes became stressful in other ways.

**Friends.** All women spoke of the importance of their friends as well as the friends of the partner during the time of caregiving. For those couples who had long established roots in the community or worked within the community at some point, they indicated there were numerous friends who were available to offer support. Many of the women spoke of friends coming over for coffee or to “check on the spouse or see if she needed anything”. Neighbours were often seen as someone who could be called upon to run an errand for the woman if necessary. For one woman, friends meant there were people who would be around when she was at work so her husband, although in

the beginning did not need to be cared for continuously, would have people to keep him company, ensure he was alright and yet still allow him the dignity of being independent. For another, friends would come and talk with her husband in the van while she ran errands in the town. For yet another woman, friends made the difference when a significant move occurred.

Easter weekend there was friends and family came to our farm with their trucks and their cattle trailers and their horse trailers, I think there was 19 units and they moved us lock, stock and barrel to town.

On the other hand, some women commented they were not expecting the withdrawal of support from friends that occurred because of their discomfort with death and dying.

The things that hurt most are the lifelong friends that avoided us - because they didn't know what to say. They felt bad that [spouse] had this condition and you almost felt like giving them a shake and saying well we're the same people with this problem.

For a small percentage of the women interviewed, close friends within the community did not exist. For one woman, most of her friends and confidants were not within the community she lived and although she indicated they were important to her and she did phone them often, there was a sense of loss of not having someone close by to simply come over and have coffee with or connect with on an intimately face-to-face level.

Even to have someone cook for you something, and see if you had friends here they would bring you over a meal maybe if you ask them to but I knew nobody.

For this woman there was a heightened sense of isolation because even though she did have friends with whom she spoke, they were not present to observe her daily or weekly life and so in her perception their understanding of the situation and circumstances was less than if they were closer by.

***Community.*** Rural communities tend to be relatively close knit according to a number of the women, and most women interviewed commented on the support they had from the community as a whole as well as specific community groups they were associated with. In some of the smaller towns, women spoke of how news carries and so soon an entire town knows when something is wrong with a member of that town. Although this, according to one woman, may, in other situations, feel like an invasion of privacy, in this particular instance it was actually helpful. She said it was helpful because she did not have time to go around explaining to everyone what was happening or stop the rumour mill. Rather, people would just start to come around and it generated a circle of enquiries from people as they continued to keep in touch with what was happening with the person, and some community members even began to visit more often than in the past or bring practical things over like meals. This was one level of community support.

A second level of support came from the connections women and their spouses had with various community groups. A couple women had strong connections to their spiritual communities and had consistent and strong support from there.

I was part of the [church] and they were always very concerned, certainly concerned when he felt he wouldn't go to church anymore because he couldn't stand for the hymns and even though you say to a person you don't have to stand for the hymns you feel everyone's looking at you. I would think there is very strong support from the church. Very strong support from people inquiring from [the wider church], if I said I can't be there I'd appoint someone to be there and do my job. No I couldn't ask for any more support.

For other women, their support came from groups meeting within the community. Heritage Committees, Kiwanis, senior's clubs, and golf clubs offered different means of support such as ensuring someone from the club came on a regular basis to visit, or members would make meals or other small things as a contribution to helping out. For one woman, the contribution of a community group was substantial and incredibly meaningful. When the local Kiwanis Club, that her husband had been a part of for a number of years, discovered he was ill, they wanted to do something to help out. This man had been in the process of adding onto the family home, a sun room, but he became too sick to continue. So the Kiwanis Club stepped in and took to the task of finishing off the room. A group of people came out to the house and put up walls and the roof and painted it the perfect color, according to this participant. By doing this, the

couple was able to spend his last days in the room, looking out into the sunshine. For her, this was the kind of support that goes above and beyond and yet meant so much.

### *Self Care*

Although self care was articulated by participants as an important aspect of the caregiving process and seen as something important to ensure a woman entering into the caregiving process knew about and did, most women found it difficult to do. No one found it possible to do on a consistent basis because most of their attention had to be paid to their partners and so their activities and care for themselves were put on hold.

Things women did indicate they tried to do to take care of themselves included; daily walks, trips into the city, outings with family members, going out to movies or bringing movies in, going to family functions, keeping up daily routines (like doing laundry), reading, trying to eat properly, praying, watching television, playing cards, cutting back on paid work, and going off to work. One woman said

I made a point of finding quiet things to do and he [my husband] would do word searches and I would do something else, some other type of book activity. [That way] we were always there together.

Although most women said they did retain at least one self care method, a number of women indicated that they actually gave up activities that they quite enjoyed and always did prior to their husbands' illness. Things such as knitting and crocheting, going out places, or participating in sports activities went by the way side during the

spouse's illness. One participant said she just couldn't get into doing those kinds of things and it took a long time after her husband died to even get back into doing things.

Another woman said

I couldn't get my mind set into reading a book or I couldn't watch TV for more than a half an hour program because it just seemed all too trivial to me. I just couldn't do it.

And a third participant said

Unless someone else's here to watch over something you can't even go and have a warm bath or even get something to eat. I would read uplifting stories to him and everything that I did to take care of me had to include him.

There were some instances when women said they would access respite services in order to go away for a short period to have some self care time. However, all of the women said that even when they had access to respite and self care time away was possible, they had a cell phone with them at all times and the respite worker or whoever was in the home with the spouse had the phone number just in case they were needed. Therefore many of the women indicated that although respite was an important part of the team, it was difficult to use for self care purposes because women were still "on call". With respect to this, one woman said she went out for a time and left her child's phone number with the respite worker. When she returned home a short time later, she discovered the relief worker was gone and her child was there. The relief worker had left because her husband had become distraught when he realized she was not nearby.

Finally every woman talked about eating and sleeping as a way of getting self care and even suggested that it would be important to encourage someone starting in the process to make sure they get nutritious food and enough rest when at all possible. However, these were also the two things that the participants said were the most difficult to get on a consistent basis. For a few different reasons, women indicated that eating was difficult at times. For instance one woman said

I would try to eat properly; everything had to be quick though because if he called out or needed something I had to run. Sometimes I wouldn't get the chance to make anything or what I had started would be burned by the time I got back so I ate nothing.

Another woman said

I tried to make sure that I ate properly but you know I did eat less because it's not very encouraging for him for me to sit there and have a full meal while he had just a little bit. Different people mentioned 'well you lost weight' and so finally I said, 'If you had been around the last couple of months, you'd understand that'. I tried to, not to be so obvious. Eating was a big thing because he didn't feel hungry and so you didn't eat in front of him.

Sleeping was another interesting topic. All the participants talked about wanting to be close to their spouse in order to spend time with them. A number of them also talked about needing to sleep nearby rather than in their bed in order to get any sleep at all. Therefore when the partner moved into a hospital bed or into a different area of the home due to need often the woman moved with him. Women talked about a variety

of different things they slept on during the last days of their spouse's life. One participant said "I bought a blow-up bed, put it in the living room and got rid of the couch and put this rocking chair close to the bed and that's when my life began, sleeping in this chair". Another spoke of sleeping on a recliner chair next to a couch that her husband had to sleep on.

However difficult sleep was though, many said it was better to be at home than in the hospital when it came to sleeping.

Sometimes it was easier to be at home and I did have Home Care in the morning and the evening and they told me I could have an overnight if I wasn't getting any sleep but once I went to sleep out there where he was I managed to get pretty good sleep.

A common theme with respect to all the participants though was regardless of how important sleep was, there was not as much sleep as was needed during the caregiving period. One of the participants suggested it might be appropriate to make someone from respite or home care available every second night or at least a couple nights a week so the caregiver could get some much needed sleep. A second participant summed it up well when she said "I'm not sure that I got any more sleep, probably less, and toward the end definitely less".

### ***Role of Social Work***

One thing that was noticeably absent in any discussion of formal supports was that role played by social workers. Only one woman spoke of having someone for them

to talk to about their personal concerns or having someone who they could process ideas, access suggestions, or just plain vent frustration. This woman indicated she was previously connected to the worker and so felt comfortable looking to her for that support. But she also said that worker was not connected to palliative care or home care and so was only accessible because of the established connection. However, all of the participants said they wished they had access to someone in this capacity that could be there especially for them. Many of the women who spoke of this desire said they did not necessarily want to go to a formal situation of an office, but would rather have that person come to the house, or sometimes even just go out for coffee together. The role of the social worker appeared to fall into two categories: support and advocacy.

### ***Support***

Women indicated that support was an important element in a social work role within a palliative care team. This support was identified as having two aspects: emotional and practical.

***Emotional support.*** The most important aspect in this role was to have someone available (not a family member) who was knowledgeable about the dying process who could support them and answer their questions, someone trained to help elicit emotions, and someone who could pay attention to the signs of a caregiver burning out or overdoing it. Women articulated this social work role in the following ways:

Number one would be you need to offer support to people who are going through this. You need to give them an opportunity to have someone they can fall back on, not a family member. Someone that they can talk to, someone that can give them just a little bit of a hand to walk through it.

Well as I said it might have been nice to have had someone on the outside, not a family member and not a close friend, because I think maybe it would have given both of us a chance to expose our feelings a little bit one to the other.

You know sometimes when you go to palliative clients they're happy to talk to you about things they wouldn't talk to their family about. And maybe that would've been an outlet for [spouse] or for me.

One woman had definite ideas of how often a social worker should be available for a caregiver but had an understanding as well of how small the resource pool is.

Someone who was there for you, you know. That's the most rewarding experience to be able to share, you know to be able to carry somebody through and that would help me. And so in terms of [social work] job if we had enough people to go around that would be wonderful; to be able to touch base with somebody at least once every two weeks; at least once every two weeks, not once a month, but at least every two weeks. Ideal would be once a week. But just to see how they're doing because people tend to feel we're doing the best I can but is it good enough and I'm all alone.

Another woman was able to articulate how she saw the role of a social worker being accessible and some of the issues she may discuss.

And that was one thing I sort of wish I had, someone to talk to you know. Home Care did come but they were there for him and there was nobody for me to talk to except people feeling sorry for me, only people feeling bad that [spouse] was dying. I really wish I had somebody who would come in or I could go to a place, not like an office, but just have coffee and tell them how I was feeling and so forth. That I really did 'cause I didn't know what to do, what to say, or it was just this is the way through it.

Finally, another woman related being a caregiver to being the spouse of an alcoholic. When her husband drank heavily, all the focus was on him and his problems, For her, having a social worker available meant she could be focused on for a while instead of only her partner having the focus.

Everybody focuses on the person that's sick which you can't help but doing but still; it's like my husband was an alcoholic, he was sober 19 years before he died but in those hard years everybody's focus, mine included, was on the drinker who was drinking and we never got a chance to spread because the focus was never on us. And that's just what it kind of reminds me of. The people who are not the problem, not that he was the problem but just to say, are so affected by the problem they're the ones that are being kind of left out.

***Practical support.*** A second area of support for a social worker was more practical in nature. From this perspective, women saw a person available to walk with

the family from the beginning of the palliative process to the end, outlining and explaining various steps along the way. One woman explained

I think it's so hard to come to grips with it and talk to somebody like even talking to somebody like the lady here who is looking after Home Care. To me it just put the final mark on things a little faster and she said to me you need to talk to [spouse] about the living will, you need to do this you need to do that. And I was petrified. ... I know even having the pastor come, I was a little worried about that because I always thought that [spouse] would have felt we were pushing it on him faster and I just think we had trouble with that, coming to grips with what was happening.

Women would have liked to know they were not alone having to explain and bring up various topics with their partners that they may feel were either difficult to discuss or they were having a difficult time coming to terms with themselves. By having a social worker involved, women indicated they would feel less pressure to understand everything and would be freer to participate in the process as it happened and really be a partner in the process as opposed to a professional in the process.

### ***Advocacy***

Many of the women interviewed expressed how alone they felt when providing care for their spouse, especially when it came to manoeuvring through the healthcare system. Therefore women indicated a second important role for a social work position was to have someone who understood the medical system and could help walk through the process and navigate the waters or be a buffer with respect to all the people involved. As one woman said, "patients and families need advocates, they really do".

Throughout their stories, women spoke about times when they felt having a consistent advocate available to them to help cut through some of the Medicare processes would have been very valuable. Women said that, at times, they were left to wait for hours in emergency rooms with no access to pain medication and a lack of understanding from staff. Other women spoke about less than adequate care their spouses received and not knowing where to go to complain or try and rectify the situation.

And I think it's good to have an advocate to cut through some of the BS that goes on between doctors and nursing and to the patient, it's like sometimes they need a shortcut somehow.

If you are visiting me during my time that I was going through this and you were walking through with me and you know what's happening at the hospital, 'This is gross I shouldn't be treated like this', whatever it was, then this would've been your role where you could have helped.

### ***Recommendations from Women Caregivers***

Women were asked what information they would like social and health care policy makers to know about the needs of women caregivers looking after their partners at home. Their answers were varied, but did reflect much of their previous thoughts and experiences. A number of recommendations referred to palliative care needs in general, while two very specific recommendations regarding needs for the caregivers emerged.

General recommendations:

- Having a nurse or someone available to frequently visit and check on the dying person as well as the caregiver
- Having phone numbers easily accessible outlining various supports available within a community and Health Region.
- Having more respite care available, ideally every second night.
- Dedicating more money in the healthcare system for palliative care services. This includes having dedicated palliative care services in each Health Region and every hospital having dedicated palliative care beds.
- Offering more training for professionals such as doctors and nurses to help lessen the communication gap between medical terminology and language that caregivers understand.

Specific recommendations for caregiver needs:

- **Support for caregiver**

All of the women emphatically indicated the need for support directly related to the caregiver. A number of participants spoke directly to the need for having a person (social worker or nurse) who could come to the home frequently to check on the caregiver to ensure she was functioning and doing alright. The primary job of this person would be as someone for the caregiver to fall back on whether it is seeking emotional support or advocacy. One woman articulated that this person would need to be someone who could see the very subtle signs of burnout because as a caregiver she

always said she was doing fine and would continue to fumble along even when things were getting too much for her and she should have actually been asking for help.

A second form of support necessary, according to participants, was access to resource information. Women requested having access to phone numbers of people available on an "on call" basis, as well as organizations and people they can access who have a role to play in the palliative care process. For example, in one community a furniture store offers its services of setting up hospital beds for people for no charge as a way of supporting the Cancer Care program. However, when she was caregiving, this was not widely known. The suggestion of producing a brochure or resource with a list of available supports and resources in each Health Region was seen as an important addition to the home palliative care program. As one woman said

Some people aren't even aware of all the help that they could get from the Home Care workers, from the palliative care workers. All the help they could get if they chose to take somebody home. A lot of people aren't even aware of that, they might even choose to do that but it's not really made available to them.

- **Training**

Women recommended having access to some type of basic training program before taking their spouse home to take on full time caregiving responsibilities. One woman suggested perhaps this training could take a similar form to current palliative care volunteer training. Many women spoke of being thankful for having knowledge due

to previous jobs where they performed some of the basic care tasks associated with this process. For example, gaining knowledge of proper lifting procedures and nutritional information were a couple areas women wanted included. As well, information of what to expect as things progress with the disease would have been seen as helpful. Understanding that personalities may change and other such things would have been helpful for these women to know prior to being in the middle of it.

### ***Summary of Findings***

I believe that the findings represent the experiences of the female caregivers who participated in the study and provided insight into their “lived experiences” in the world of palliative care. The importance they placed on communication and support systems, as well as the importance and difficulty of self care were strong findings, ones that were not completely surprising to me. However, they definitely placed more emphasis on communication and the lack thereof than I would have expected. This was evident not only in the content of the interviews but also was reflected in the need for many of the women to debrief about some of their experiences of communicating with health care professionals. The lack of available social workers within palliative care teams contributed to a definite gap in services. Women very clearly articulated their desire for someone who could have been available to advocate and offer support to them and their entire family. Overall, all participants were satisfied with their decision to care for their partner at home and their positive experiences outweighed any negative experiences they experienced. This can be attributed to the great work of the

palliative home care programs available in the rural areas. The recommendations they made with regards to support and training were insightful and thoughtful and add weight to the discussion of results as well as the overall conclusions and recommendations.

## Chapter V: Discussion

The overall objective of this study was to contribute to the understanding of the factors which shape the support needs of rural women caregivers as they offer palliative care at home to their spouse (common law or life partner). The narrative research using semi-structured interviews was necessary to gather sufficient data from this small sample of women to address the specific objectives asked in this study.

The first objective was to understand the experiences of women caring for their dying spouses in rural Manitoba. By using a narrative analysis and recording the interviews, women were allowed to tell their stories and there was opportunity to be “engulfed” in the story as it was being told. The rich descriptions and information offered helped to more fully understand their experiences. The second objective was to determine women’s needs for support within the context of caring for their loved one who was dying. It became evident that the need for support came from all areas within the circles of support, as described by Davis (2005). The third objective was to explore the availability and gaps in support. The women were clearly able to identify where they received support and where support was lacking. There was clear indication that there is room for improved supports within formal support settings.

The findings of this study reinforce that the support needs are multi-faceted and often individualistic depending on the current situation of the caregiver. However, effective communication; comprehensive support systems, and self care were significant needs discussed by each woman. As well, the absence of social work from the

palliative care team was seen as a gap needing to be filled. The findings also add to a gap in the existing literature by focusing entirely on the female partner of the terminally ill person. The following discussion will explore these findings within the context of existing literature.

### ***Women's Experiences***

This study showed the experiences women had caring for their husbands at home during the last stages of their life were profoundly life giving but also posed a number of challenges. Each woman talked about how the positives simply outweighed the negatives and therefore they chose to care for him in the home. They spoke of how important and satisfying it was to be able to be with her husband during this time; the ability to have more quality time at home together, offer him all of the comforts of home, and continuing with their daily lives while doing those extra caregiving things such as dressing and bathing for him. They each spoke of how important it was for them to do the caregiving work as opposed to having a stranger do it. At the same time, each woman said they had a good relationship with their spouse and that perhaps this made doing palliative care at home easier. Some women did talk about it possibly being difficult in the event their relationship was more strained. However, this study also established that women experienced frustrations in the caregiving process in areas that were personal, practical, and systemic in nature.

These findings are consistent and supported by work done by others. Research has shown (Boerner, Schulz, & Horowitz, 2004; Cohen, Gold, Shulman, & Zuccherro,

1994; Hearson & McClement, 2007) that caregiver satisfaction is directly related to the relationship between a caregiver and the care receiver. The satisfaction of the caregiver is enhanced when the relationship to the care receiver is central to the caregiver's life, such as in the case of a spouse and the task of caregiving is done out of a sense of duty and love for that person. Research also shows (Osse, Vernooij-Dassen, Schadé, & Grol, 2006) under these conditions more than 85% of caregivers indicate that positive experiences outweigh negative ones. These positive feelings have included companionship, fulfillment, enjoyment, and the satisfaction of meeting an obligation and providing quality of life to a loved one.

Research also reports that in addition to the rewarding aspects of caregiving, there are the realities of stress and exhaustion (Hearson & McClement, 2007); a lack of support for practical needs such as shopping and cleaning (National Institute for Health and Clinical Excellence, 2004); a lack of support for personal problems; a lack of support providing direct care to the loved one (Osse et al., 2006); and a lack of communication with health care professionals (Jo, Brazil, Lohfeld, & Willison, 2007).

### ***Women Caregiver's Needs***

This study showed that women's needs during the palliative caregiving process did not fit neatly into any one type of category. Rather, needs were often determined by the situation as it arose, therefore giving rise to the unique and individualized nature of caregiving. However, three broad categories were discovered that encompassed many of the needs of women caregivers. These included; the need for communication; the

need for support systems; and the need for self care. Within these broader categories were components that took on more or less importance for the women depending on their specific situation. These findings support the work of Aoun et al. (2005); The National Institute for Health and Clinical Excellence (2004); Thomas (2003); Thomas et al. (2001) and other authors cited in the literature review.

### ***The Need for Communication***

Although none of the women in this study had been placed in this type of caregiving capacity prior to this experience, all clearly identified communication as their most important need. Most of the women did not have a positive experience with respect to communication, especially when it came to the health care professionals. This is consistent and supported by other research that has also shown problems with communication between family members and health care professionals and have explained that the importance of effective communication between families and health care professionals is paramount (Jo, Brazil, Lohfeld, & Willison, 2007; Kristjanson, 1986; Northouse & Northouse, 1987; Stedeford, 1981). According to Aoun et al. (2005)

although the negative impact of caregiving for a relative/friend with a life threatening illness has been well documented, research has demonstrated that caregivers providing support to individuals receiving palliative care report unmet needs for information and communication (p. 552).

Women in this study then articulated two main areas necessary for successful communication. These areas included team work and accurate and timely information.

**Team work.** The women in this study had a variety of experiences with team work. To begin, there was no one definition of team work that every woman used to define what they saw as important in this area. For some, being part of the team was to be recognized and valued for the skills they possessed; for others, being listened to and taken seriously was the important concept within the team. However, regardless of the definition a woman used, each reported that to have a successful team experience meant they wanted and needed to be an integral part and that each had a valuable part to play. They needed to be involved in making decisions as they were being made and they wanted input into these decisions and they wanted and needed to be taken seriously when they spoke of something that was happening. Women articulated needing to be listened to and their input considered. These results reflect and are consistent with results of previous studies. According to Thompson (2007), there is incredible importance in involving women in both the decision making process, as well as taking time to listen to them. Hearn and Higginson (1998) suggest that an effective and communicative team is essential for achieving the appropriate outcome in palliative care. Finally, McIlfatrick (2007) identifies the need for improved communication within the health care system. He further states that a lack of co-ordination between members of the primary health care team may be one of the possible barriers that lead to this poor communication.

***Accurate and timely information.*** This study found having access to information was extremely important to the woman during this process. Consistent with Kristjanson (1986) and McIlfatrick (2007), women wanted information about their spouse's illness, including timelines, what to expect, and how best to care for him. Interestingly, when asked where women gathered information from, the first line of information gathering was said to be the internet and the second from observations. Not one woman indicated the doctors or other health care professionals were a valuable primary source of information unless they asked a specific question. Only at that point did women indicate they received adequate information to answer their questions. Perhaps this was due to the frustration in the communication that was felt by most women when it came to dealing with the doctors and the health care system.

Good communication is a prerequisite for enabling patients and carers to make informed decisions about care. Good communication skills are therefore key to the delivery of effective supportive and palliative care services, but patients and carers frequently report that the communication skills of health and social care professionals are poor. Some professionals tend to make assumptions about the level of information required, rather than asking patients what they want to know (National Institute for Health and Clinical Excellence, 2004, p. 56).

Often women felt the information they were given by doctors was incomplete or cushioned in promises that could not be kept, but they knew the flow of information was controlled by health care providers and women had neither the time nor energy necessary to demand this information.

The majority of women reported being let down when it came to accessing information. This finding is supported by earlier studies that discussed difficulties in receiving adequate information from health care professionals; things such as contacting physicians, being refused information, getting access to existing information, accessing community supports and how to care for themselves are just some issues discussed in literature (Bond, 1982; Kristjanson, 1986; McIlfatrick, 2007; Thielemann, 2000; Wei-chun Lin & Chao-jung Tsao, 2004).

### ***The Need for Support Systems***

Davis (2005) explores the idea that all people have around them circles that constitute levels of support. As a person is in the middle of the circles, levels of support move outward from the most intimate to professionals. There are four circles around every person:

- Circle One – the circle of intimacy: those with who we share great intimacy, heartfelt emotions, secrets. This may or may not include family members.
- Circle Two – the circle of friendship: friends or relatives, who we go to dinner with, see a movie, do not necessarily see on a regular basis.
- Circle Three – the circle of participation: where one belongs such as organizations, spiritual groups, work, clubs.
- Circle Four – the circle of exchange: people paid to be in our lives such as doctors, nurses, therapists, government programs.

Those findings support this study as this research found that indeed women experienced a need and desire for support in all these areas; however they articulated it

in terms of formal and informal supports. This study also aids in filling a gap in knowledge with respect to adequate support for informal carers from a gender analysis perspective.

**Formal supports.** This study found that women's experience with the formal supports in the palliative care team was mixed. Most experiences with doctors, especially the specialists were less than desirable and communication with these doctors was very strained. Of all the doctors women came in contact with, the most supportive tended to be the general doctors in the rural hospitals. According to one rural doctor, this may in part be because rural doctors do not have the ability to decline patients from their practice. Because they may be the only doctor in a large area, it is in their best interest to get along with as many patients as they can and this often means taking extra time to explain things and answer fully all questions (a rural doctor, personal communication, January 16, 2008). Further, specialist doctors tend to walk away from patients and families after giving news of diagnosis and prognosis even when questions still needed answers (Clarke & Ross, 2006).

Nurses were another group of formal supports that women articulated. This group produced mixed results with respect to support. Nurses working in the acute care setting were seen as less supportive than those who worked within the home care and palliative home care setting. Work done by Holmberg (2006) found

In general practice, registered nurses tend to overlook systematic assessment and intervention with the patients' families when family

members are not seen as important in the care and have not been invited to participate. Interactions are invited, on the other hand, when the family members are seen as important participants in caring for the patient.<sup>1</sup> Specialist nurses in palliative home care more often focus on the delivery of emotional care and support to patients and their families and invite family caregivers to participate in the care, to the benefit of the patient.

A survey conducted by McDonnell et al. (2002) (cited in Clarke & Ross, 2006) found that nurses' perceptions of palliative care in the general wards found that "most were confident undertaking physical care, but few felt confident discussing death and dying with patients" (p. 34). They further found that nurses tended to be excluded from the team when it came to giving news about the diagnosis and direction for care and this often left them feeling at a loss for what to do next.

Women in this study identified other formal supports such as ambulance services and pharmacists as very supportive to them during this process. No existing literature was found to support or refute these findings and perhaps there is a gap in literature about more distant formal supports and their roles in the palliative care team. Given that rural locations often lead to closer knit communities and people knowing what is happening in the area and what needs are present, it is possible that formal supports, especially those that live within the community move outside their prescriptive boxes to also take on the roles of informal supports.

Although the Government of Canada has a Compassionate Care benefit that offers caregivers who qualify an amount of money for a period of time so they can dedicate their time to caring for their loved ones, this research showed that few women may actually qualify for the funds. Not one woman in the study identified this as a support they considered and further, within this study, only one woman qualified for the government caregiver benefit as she had enough hours and a long enough period of working; however she chose to continue working through the process and so never took advantage. This study shows the need for a more thorough gender analysis of this benefit to really determine if it is beneficial to women.

***Informal supports.*** This study indicated that family, friends, and community organizations and groups were very important during the caregiving process. Women who had family members close enough to come to the home on a regular basis were invaluable when it came to support. By having other family members present, women were able to do things they may otherwise not have been able to do if they were to have had to rely exclusively on respite or home care. Friends gave opportunities to continue to socialize as well as provide practical support such as meals and transportation and community organizations and groups offered a variety of services such as practical, emotional, and spiritual support.

Research is limited with respect to informal support needs for a female caregiver and this study helps to fill this gap in literature. References can be found that address the informal support needs of a family and friend caregiver and those studies support

the findings in the current research. Clark and Seymour (1999), as cited in the literature review above, found that having adequate support, including informal support, available to a caregiver increases the success rate of home palliative care. Milberg and Strang (2004) and Waldrop (2007) found informal support directed to the caregiver increased the carer's manageability of the caregiving situation. Three main types of supports were identified as being provided by family, friends, and community service organizations; emotional, practical, and informational. Emotional included social contact and communication (not necessarily illness-related), caring, listening, and being open and honest; practical and informational included various tasks related to everyday living such as social activities and household tasks. One issue addressed by Waldrop but not observed within this research study was the change in interpersonal dynamics within family and support networks. He indicates that for some, intensified conflict can occur during this time while for other greater cohesiveness is the result.

### ***The Need for Self Care***

This study confirmed that women's need for self care continues throughout their partners' illness. Women indicated they did various things prior to the illness as a way to look after themselves and many tried to continue doing some of the same things during the time she cared for her husband. However, women reported it to be difficult to continue with many personal activities done as self care because daily tasks of caregiving took precedence and their own needs often had to go by the way side. In particular, women discovered it to be very important to get good nutrition and enough

sleep, at the very least, during the caregiving process. However, as other literature has reported, (Waldrop, 2007) many women found they were unable to get enough sleep because they were up during the night tending to the needs of their partner; they began to sleep very lightly and so would be interrupted by any little noise, or they were sleeping in areas and on furniture that are not normally meant for long time sleeping.

Women also reported having access to respite on occasion in order to get tasks done that required them to leave or to get a little bit of self care. However, according to the participants, respite did not completely give rise to self care time. Although women may have been able to physically leave their home, not one of them reported being able to mentally and emotionally leave. This finding has been reported by Harding and Higginson (2003) and Strang et al. (2002) who also indicated that although respite aims to provide the carer with time away and the rest required, it does not necessarily fulfill this in an acceptable way.

Finally, this study found that women are incredibly resilient when it comes to caregiving. On a number of occasions, women drew on inner strength to continue along the journey until they completed their role upon the death of their husband. For those women who had close family or friend support, the resiliency appeared to be greater. This is consistent with work by Glicker (2006) and Leipert and Reuter (2005). Women indicated this was not always an easy task but because it was one they wanted to do, it was seen as important for the woman to be perceived as being "okay" by other professionals. Often times when women were asked how they were doing, instead of

recognizing they could use extra support, they simply indicated everything was fine. This may in part be because women caregivers have a difficult time expressing their own needs because they are so focused on their partner. This supports work by the National Institute for Health and Clinical Excellence (2004) who found that family members usually try to keep things going and so remain “invisible” to health and social care professionals. However, some participants also indicated that their caregiving was done at the expense of themselves and in hindsight they did experience burnout or they developed their own health issues. Ensuring someone was available to “call them on that” would be important. Harding & Higginson (2003), the United States National Association of Social Workers (2004), and the United States National Comprehensive Cancer Network (2008) have reviewed this same phenomenon and found that only when caregivers are sure that support and services are not going to be taken away or diverted from their loved one are they likely to confidently accept support for themselves.

### ***Gaps in Support***

Women offered clear messages about where there were gaps in support for them during this time. As described above, types of supports needed included open communication with access to information and a team approach to care, support systems that incorporated all areas in the circles of support, and self care. The women overall were satisfied with the support they received from friends and family. There were mixed reviews about the support they received from professional health care

people. In general, professionals who attended to the loved one at home got more positive reviews than those associated with hospitals for example. There were instances though where having access to resources such as a social worker would have enhanced the palliative care team.

Women did have concrete ideas about sources of support that could be developed. The need for a social work position (or one woman indicated a highly trained volunteer) within the palliative care team was discussed. This position would be responsible for connecting with each person at the beginning of the cancer process and working with the loved one and their family for the purpose of offering advocacy, emotional and practical support, and providing information. This is consistent with the United States National Association of Social Workers (2004) who indicates

Interdisciplinary teamwork is an essential component in palliative and end of life care. Social workers are integral members of a health care team. Social workers should advocate for the views and needs of individuals and families in palliative and end of life care within the team, and should encourage and assist clients in communicating with team members. Often, clients, families, and team members rely on the expertise of the social worker in problem solving concerns and conflict resolution. (p. 24)

Other literature (Rodway & Blythe, 1992; Stein, 2004) indicates that often health care professionals, such as doctors, have a narrower view because they get caught up in their areas of expertise and do not see the larger picture and the maze called the health care system. In this case, a social worker in an advocacy role could navigate through

some of this system to ease anxiety and stress felt by caregivers and patients as they are experts on health care teams in facilitating communication and providing emotional support. Clausen et al (2005) comment that the role of the social worker in palliative care has four main contributions and these resonate with the four key elements by Sheldon (2000) discussed in the literature review. The findings of this study were contrary to Wennman-Larsen and Tishelman (2002) who indicated in their study that caregivers, although they needed someone to talk with through life transitions, did not ever mention health professionals as possible supports for themselves.

Women did recognize that needs may be different for each caregiver depending on her circumstances, her level of comfort and expertise in the caregiving role, and the supports she has available to her. This is similar to findings by Zapart, Kenny, Hall, Servis, and Wiley (2007) who found the role of social work may be to provide emotional support in one case but not in another if peer support is available. This social work position then needs to be flexible to be more involved at some points and less at others. Their role would free women of the responsibilities of liaising between their loved one and the health care professionals and advocating on their own behalf and give them the opportunity to concentrate on their relationship with their spouse.

### ***A Revised Conceptual Model***

Reflecting upon the responses of the participants, the work of Lazarus and Folkman (1984) and Folkman (1997) on the transactional model of stress and coping offers a good beginning to how these women articulated their experiences. However, it

is important to make some revisions to this model to more accurately reflect the women in this study.

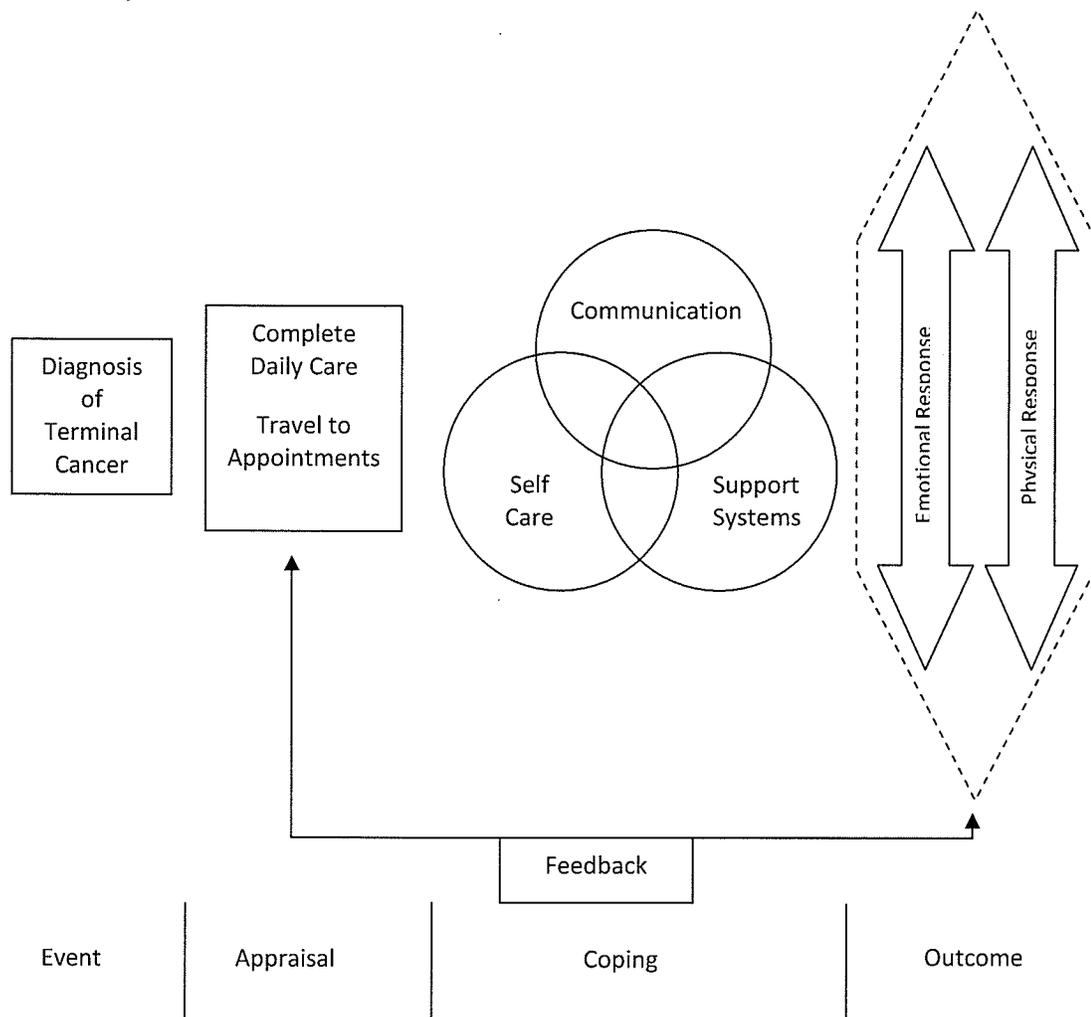


Figure 7: Conceptual Model for Female Caregiver of a Spouse with Terminal Cancer

For the caregivers in this study, the stimulating event that initiates the stress response was the diagnosis of terminal cancer. According to Dumont, Turgeon, Allard, Gagnon, Carbonneau, and Vezina (2006) a terminal cancer diagnosis can lead to severe psychological distress and this distress continues to increase as the loved one loses autonomy. This distress was seen to be increased when the caregiver was a woman.

The appraisal phase of this model occurs as the woman assesses what kinds of tasks and responsibilities she is going to have as a result of doing palliative care at home with her spouse. Women in this study indicated they were responsible for the overall daily care of their husbands including such things as feeding, bathing, and other physical support; emotional support; giving of medication; travelling to medical appointments; and at times leading the overall palliative care team. It is also during this time that the caregiver assesses the length of time she may possibly be in this caregiving position.

The availability of resources to the women in this study had a large impact on their ability to cope. Therefore within the third phase of this model, women assess what resources are available for them to draw on during this time of caregiving to help them cope and manoeuvre through their stress. It was clear during this study that women who had a balanced combination of good communication, support systems (both formal and informal) and an ability to do self care, coped with their stress much more effectively than those who had only one, two, or perhaps none of these resources. This then leads to the range of outcome. Depending on the coping mechanisms available, the level of physical and emotional response (stress) may be high or low.

As long as the stressor of caregiving is at play, the woman is subject to this process through a feedback loop where her physical and emotional responses move back to the appraisal stage and she again reassesses her responsibilities and finds and utilizes her resources.

This model adds to the work of Schoon (2006) who indicated that the level of resilience among people increased as they had access to better psycho-social elements earlier in life. For example, women who had community supports available to them prior to the illness coped better and were more resilient than those who did not have those supports available. At the same time, women who indicated a good communication system within the palliative care team, felt better about their ability to cope than those who were stressed with not feeling as part of the palliative care team or not having all the information they needed to do the caregiving. For each of the women who indicated they had good communication supports, they also indicated in general they were able to speak up for what they wanted.

## Chapter VI: Implications, Recommendations, and Conclusions

### *Merits of the study*

As health care in Canada continues to change and move toward community and home care, more and more people are remaining at home until close to death or until death. This has a significant impact on those who care for them. According to the Standing Senate Committee on Social Affairs, Science and Technology (2001), there are currently more than three million Canadians, mostly women, providing unpaid care to ill family members in the home and more women are being conscripted into unpaid health care work, doing so without training and with little support. However, there is limited research offering a gender analysis of rural caregiving. Caregiving research that is available seems to downplay the significance of impact on women. As traditional expectations call for women to take up the caregiver role, and rural communities are often more traditional in nature, it stands to reason that rural women take on the majority of caregiver roles. Yet their voices remain unheard in policy and decision making about what support is offered them or needed in this time of health care reform.

As well, there is much research available about the needs of a palliative care patient, either at home or in hospital, but there is little understanding of what caregivers' needs are to remain healthy enough to support the patient. Therefore, this research is crucial in bridging gaps of knowledge in service and needs with respect to the caregiver. It is important that the caregiver is healthy and heard as she is the

constant carer. She is responsible for communicating with and understanding both the professional and the patient. She is the person who often ensures communication is accurate, needs of professionals and spouse (common law or life partner) are met and the complete comfort of her spouse (common law or life partner) is attended to. Unless resources and support are offered the caregiver may not even take the time to think about herself.

Conducting a narrative analysis offers the opportunity to develop knowledge of the subjective experience of women in caregiving by co-creating the research, not remaining external to it. This offers merit from two levels. Relationships are crucial to a successful research process and narrative analysis offers the researcher the opportunity to develop a relationship with participants, empowering them to tell their stories, while generating information for analysis and dissemination. It also calls for reflexivity of the researcher. A narrative approach allows room for me as the researcher to be transparent and clear about my own thoughts. To be engaged in the process is also to keep myself accountable for decisions made in description, analysis, and interpretation during the research.

### ***Limitations of the study***

There are potential limitations to this research and the use of narrative analysis methodology. Issues such as time and limitations in sampling are important to consider in this study. Because it is part of a degree process, I only took up to three months to conduct interviews. This is a limitation if potential participants were unable to

participate within this timeline. Also, it was limiting as only five of the six targeted Health Regions responded to my call for support and my total participant count was five. Because I only conducted one interview and travel distance was a factor, I chose to rely on email or phone interviews for subsequent follow-ups if necessary. When doing narrative research, this is not often the best possible way to conduct an interview as body language and non-verbal cues are not possible to see.

I only recruited participants who had provided palliative care with people dying from cancer. However it must be acknowledged that cancer is not the only disease in which palliative care services are used. The needs of a spouse (common law or life partner) dying of cancer may be very different than the needs of a spouse (common law or life partner) dying from another illness such as amyotrophic lateral sclerosis (ALS), congestive heart failure, Alzheimer's, or chronic obstructive pulmonary disease. This limitation means that my study can only be understood in relation to those dealing with cancer until such time as further or more in-depth studies that involve caring for persons with other diseases can be conducted.

Because this research looked back at an intense point in time, it may have been difficult for participants to recall with accuracy what needs and wants they had during the time they were caring for their spouse (common law or life partner). It may also have been difficult to recall what resources were offered during that time. Also, people grieve at different rates and intensities. Although I sought participants who are one to five years past the actual death of a spouse (common law or life partner), it does not

mean they are all in the same stage with their grief. This can be a limitation as the intensity of grief still present may make information gathering difficult.

The health care system is in a time of rapid change with new programs being added, especially as palliative care programs become more developed and the needs of participants (patients and formal and informal caregivers) within this program are enhanced. Therefore because all participants did not come from the same health authority and utilize services within the same time period, it is difficult to compare the experience or accesses to the same type of programs and service delivery.

Narrative analysis requires a balancing act between making generalizations and paying close attention to the narrative form and thus the method is slow and painstaking. It is the responsibility of the researcher to pay attention to the organization of speech, social discourses that shape the story, any nuances that may be present and any other contexts that may have importance (Riessman, 2002). However, as the researcher, I also have my own context and it inevitably played a part in the how I interpreted words, phrases and other such context.

As a feminist, power is an ethical issue for me. Those I chose to interview in research definitely invokes ethical issues relating to power and needs to be taken into consideration. Because most of the participants were recruited through the help of the palliative care co-ordinators or their designates, it is important to acknowledge their power in making the decision of who to send the information to. Only four people were recruited from each health region. It is impossible for the researcher to know what

process each health region used: random, people associated with a grief group, people associated with a palliative care volunteer program for example.

Only five rural women participated in the research and this cannot possibly account for the wide range of communities and the isolation between women living in very remote areas and those living closer to cities. Between these categories, there are differences in community supports available. Also, specialized cancer services and many hospitalizations were accessed within one major centre, Winnipeg. In other communities further away, different major centres such as Brandon may have been accessed for many of these specialized services and this too may contribute to different experiences. So it is important to understand the limiting factor of only being able to reach a very small number of communities.

### ***Implications for practice***

It became clear through this research that a recommendation for specific health care providers within the palliative care system dedicated to addressing the needs of the female spouse (common law or life partner) be hired. The person may have a number of responsibilities including explaining the dying process to the spouse (common law or life partner), acting as an advocate within the health care system, and offering bereavement follow up.

Because dying and bereavement are very emotional processes, perhaps a social worker would be the most appropriate professional to address the above role. A social

worker possesses counseling skills necessary to navigate emotional issues and also has mediation skills that could help in navigating between the health care system and the family. Social work practice emphasizes both the person and their environment which could “shed more light on the process of palliative care: its social and cultural dimensions, adaptations required by others and the interaction of patients, families, professional and the larger systems within which they function” (Rodway & Blythe, 1992, p. 429).

To be a nurse or doctor caring for a dying patient requires specific sets of formal training. However, there is no recognition that perhaps the female spouse (common law or life partner) may also need some training (formal and/or informal) and education to fulfill their role of caregiving. This study found there are specific needs that the caregiver has that could be met with a training or education program that the caregiver could have access to during the dying process, including perhaps pieces of an already established palliative care volunteer program. As well, the creation of a pamphlet or booklet within each health region outlining available services within the region and contact numbers could be produced and given to each person as they look at beginning the caring process.

As practitioners look at planning interventions and developing supportive services for female caregivers it is important to develop programs looking specifically at the needs of the individual. This study found the needs of female caregivers to be very individual; therefore a generic program would not meet the needs of every female

offering palliative care. According to the National Institute for Health and Clinical Excellence (2004) in England and Wales, although a number of models for providing help and support has been identified, no one has been found to meet the needs of every caregiver, therefore expanding services to include multidisciplinary support may meet the needs of the caregiver.

### ***Implications for education***

There is a need to educate health care professionals about informal caregiver needs and the importance of their role in relation to the care of the dying. In order for professionals to do their work effectively they need to understand and be prepared to address these needs.

The need for information from professionals such as doctors, nurses, and social workers may be important for the caregiver. Therefore effective communication skills may alleviate stress felt by the female caregiver. This also goes along with a professional caregiver's understanding of how their actions and inactions impact the perception of the female caregiver. Professionals who are unable to communicate with a female caregiver as an integral part of the team and offer her comfort and compassion can cause the female caregiver to see professionals in a less than supportive capacity. Therefore, professionals must understand the importance of compassion and comfort not only for the dying person, but also for the caregiver.

### ***Implications for research***

The study focused on only one person as the primary caregiver – the female partner. However the entire family unit is affected by the impending death of a loved one. Therefore further research examining each member's role and function is necessary to understand the full impact of the caregiving experience on a family.

The study also only focused on those women whose spouse (common law or life partner) has died from cancer. However, palliative care is necessary and used in the care of persons with many other illnesses as well. Therefore further research focusing on other uses of palliative care is necessary to understand the full impact of resources and supports needed by caregivers to care for a spouse (common law or life partner) who is receiving palliative care in the home.

There is an increase in the number of men who are taking on the primary caregiving role for their spouse (common law or life partner). Therefore more research is needed to adequately determine the needs of those men as they provide care.

As this study has limited diversity in ethnicity and excluded the Aboriginal population on reserves, further research with different ethnic groups or with the on reserve Aboriginal population may be valuable to further understand what role culture plays in palliative care needs.

Finally, because all the research participants within this study were heterosexual, married women, it would be important to conduct further research targeting women in

common law and homosexual relationships in the caregiver role to understand if their needs match the needs indicated within this research.

### ***Recommendations***

A number of recommendations have been developed from suggestions and needs articulated by the participants. As well, recommendations for further research areas are included.

1. Specific health care providers within the palliative care system dedicated to addressing the needs of the female spouse (common law or life partner) be hired. Because death and bereavement are emotional issues, perhaps a social worker trained in meeting the emotional needs of a person is the best discipline to hire.
2. A training or education program that a caregiver could have access to during the dying process, including perhaps pieces of an already established palliative care volunteer program to meet the specific need of the caregiver.
  - a. A pamphlet or booklet be produced in each health region outlining the supports available with phone numbers for anyone choosing to care for their loved one at home.
3. As practitioners look at planning interventions and developing supportive services for female caregivers it is important to develop programs looking specifically at the needs of the individual and not produce generic programs.

4. Education of health care professionals about informal caregiver needs and the importance of their role in relation to the care of the dying.
5. Education of health care professionals on the importance of supportive and compassionate communication ensuring a female caregiver is viewed and related to as an integral part of the care team.
6. Further research examining each member's role and function is necessary to understand the full impact of the caregiving experience on a family.
7. Further research focusing on other illnesses and diseases using palliative care is necessary to understand the full impact of resources and supports needed by caregivers to care for a spouse (common law or life partner) who is receiving palliative care in the home.
8. Further research is needed to adequately determine the needs of men as they provide palliative care for their partners.
9. Further research with different ethnic groups or with on reserve Aboriginal population may be valuable to further understand the role culture plays in palliative care needs.
10. Further research targeting common law and homosexual women in the caregiver role is needed to understand if their needs match the needs indicated within this research.

## **Conclusions**

**Reflexivity.** Studying female caregivers of husbands, spouses, and partners with terminal cancer has been a highly emotional experience for me. I had the opportunity to sit in homes, enter into the lives of individuals, and listen to very personal stories of people who had experienced the death of their loved one first hand. They shared with me their pain and sorrow at losing their loved one, their anger and frustrations especially when things did not move smoothly preventing more quality time to be had, and even their contentment with how things happened and what it has meant for their life now. I understood that their caregiving was done out of deep love and devotion to their spouse and was never seen as a burden or a mistake. They each shared how incredibly glad they were to have had the opportunity to share that time in their spouse's life and were comforted by the fact that they knew they had provided the best care possible.

Their stories touched me in a very personal way. This definitely brought back the emotions that were present when my mom was offering care to my dad and those feelings of grief in the memory of his death. I was able to deeply empathize with these women in their journey and relate to many stories as they were told and I had to continually assess where my personal process of grief was in relation to the research. As a researcher, I believe we always need to be prepared for the emotional upheaval such studies can bring. Past death experiences of friends or family can resurface and one may need support for dealing with these again. As well, similarities in stories or situations

between participants and researchers may create heightened awareness for a researcher that similar things can happen to them.

Using a narrative analysis meant I had to listen to the interviews a number of times and then read and re-read transcripts. Each time I sat to do this, waves of emotions washed over me, and this continued again and again even up to writing up the findings. I came to appreciate more closely what it would have been like to live in that situation for that period of time. I also wonder if this is what it may be like to work with death on a daily basis and given that, if doctors, nurses, social workers and other who deal with this daily use mechanisms to protect themselves from those sometimes overwhelming emotions. However, I always found myself perplexed about how the women described some of the interactions they had with some health care professionals. The sense of uncaring that women and their loved ones faced at the hands of professionals was very sad to me. I truly believe there always needs to be respect at the very basis of everything we do.

**Conclusion.** In conclusion, this study sought to discover the support needs of female caregivers offering care to their spouse (common law or life partner). Within society, the role of caregiver has almost exclusively fallen to women as a part of her duty and yet there has been a lack of research specifically looking at women's needs for support. Utilizing a narrative analysis, five women were asked to recount their stories of caregiving focusing specifically on what they needed for support during that time and

whether it was provided or not. The women articulated a number of categories of need including communication; support systems; and self care.

Although some communication was present, most women were frustrated with the lack of communication between health care professionals and themselves. Women often felt left in the dark and not taken seriously when speaking of issues. Support systems were needed in all areas including family, friends, community and spiritual organizations, and health care field. When women had a balance of both informal and formal supports, they found a more positive overall experience of caregiving. Women who lacked in any of these areas had a more difficult time with coping on a daily basis. Finally self care although important was found to be difficult to consistently do. Women tried their best to take care of themselves but found that time often lacked and other tasks would take priority.

In terms of social work, it appears there is a gap in the palliative care teams with respect to having a social work presence available to women caregivers. Each woman spoke of how helpful and valuable such a person would have been during this process and yet no one had access to such a person. The role of this person could consist of advocacy, emotional and practical support.

The hope is this study may be used as part of a continuum of research that tries to help health care professionals understand more fully the needs of the unpaid caregiver, and that public policies being made take more seriously the needs of women and incorporate their voices in policy decision making.

On a personal note, it has been an amazing privilege to work with the 5 women who agreed to participate in this study. I have learned so much from them, both of how things have changed and how some things haven't come very far.

Most surprising to me in this process was how much of the current literature even from many years ago still reflect the same issues that these women dealt with. Perhaps this is also my most distressing finding as well. Communication continues to be an issue today as it was twenty years ago. Because we all use our own professional languages, perhaps it will always be an issue.

However, the women I worked with certainly showed confidently how they coped in the face of adversity and how their resiliency has moved them through the palliative care/death process to bring them to where they are today – willing to share their journey with others and I wish for them continued healing and a long healthy and happy life.

It has also been a privilege to work with such a professional committee who has continually supported and challenged me to make this research better and for that I thank you.

Finally, I have grown so much through this journey, from beginning in 2005 until now, I have learned so much professionally and personally. This study as the final piece of this journey has taught me about my passion for research and at times my dismay for it. There were many ups and downs to struggle through, both in terms of the actual

research and the balancing of time to do it. However, it was all very worth the juggling act called life.

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**Appendix A**

***Map of Manitoba's Regional Health Authorities***

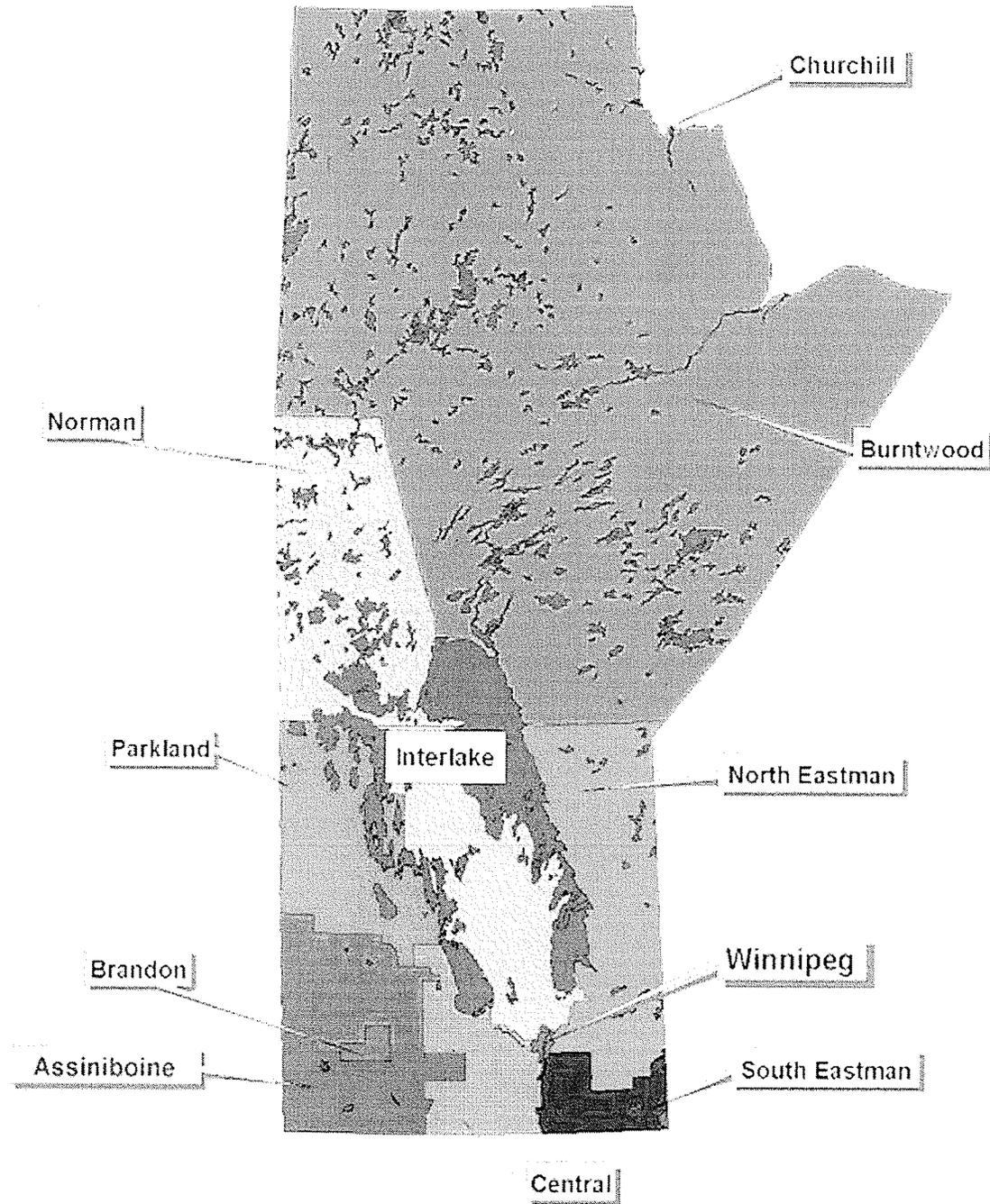


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**Appendix B**

***Call for Participant Flyer***



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

**Transcending Death by Living: Needs of Rural Manitoba  
Women Caregivers Providing Care for their Spouses  
(common law/life partners) with Terminal Cancer at Home.**

Researcher: Sandra Taylor, BSc, BSW, MTS    Advisor: Tuula Heinonen, PhD  
MSW Candidate    Associate Professor  
Phone:    (Social Work)  
Email:    Phone 474-9543

**Are you a rural woman who cared for your spouse (common law/life partner) at home in the terminal stages of his/her cancer? Would you like to share your experiences?**

My name is Sandi Taylor and for my Master's Thesis as a student for a Masters in Social Work degree, I am conducting research to examine:

**The needs of rural Manitoba female spouses (common law/life partner) who provide care to their partner at home in the terminal stages of cancer.**

- Are you a woman who lived in rural Manitoba when your spouse (common law/life partner) was ill?
- Did you live off-reserve?
- Do you speak and read English?
- Did you have primary caregiving responsibility at home for your spouse (common law/life partner)?
- Did your spouse (common law/life partner) die more than one year ago and less than six years ago?
- Would you like the opportunity to share your experiences?
- Would you be open to talking about supports and resources that you think are needed when providing care at home?

If you answer yes to these questions, I would be interested in speaking with you.

**Your commitment:**

An in person interview with me that will last approximately 1.5 to 2 hours and will be done in person at a time and place convenient to you.

If you are willing to participate in this research project, please phone me at your earliest convenience at xxx-xxxx and I will give you more information and answer any questions you may have.

Thank you for your contribution to this research.

## **Appendix C**

### ***Ethics Forms for Regional Health Authorities***

**Central Regional Health Authority**

Regional Health Authority  
Central Manitoba Inc.



Office régional de la santé  
du Centre du Manitoba inc.

**RESEARCH ETHICS REVIEW COMMITTEE**

*RESEARCH ETHICS REVIEW*

*GENERAL INFORMATION*

**This section must be completed in full by the Researcher(s) or Central Region  
Research Ethics Review Committee.**

1. Title of project

Transcending Death by Living: Needs of Rural Manitoba Women Caregivers  
Providing Care for their Spouses (common law/life partners) with Terminal  
Cancer at Home

2. Name(s), titles & contact information of Primary Researcher(s)

Sandra Taylor, BSc, BSW, MTS, MSW Candidate

Phone:

Email:

3. Brief summary/description of research project (include the question as stated in the request)

The purpose of this research study entitled *Transcending Death by Living: Needs of Rural Manitoba Women Caregivers Providing Care for their Spouses (Common Law/Life Partners) with Terminal Cancer at Home* is fourfold: 1) to understand the experience of women who cared for their dying spouses (common law/life partners) in rural Manitoba; 2) to determine what women caregivers needed in terms of caregiver supports in home palliative care; and 3) whether those supports were available and if so, from what source; and 4) what the quality of those supports were from the perspective of the female caregiver. Put another way, the central question is: What do rural women caregivers say were their support needs when they provided palliative care at home to their spouse (common law/life partner)? The hope is this study may be used as part of a continuum of research that tries to help health care professionals understand more fully the needs of the unpaid caregiver, and that public policies being made take more seriously the needs of women and incorporate their voices in policy decision making.

Using narrative research, the researcher describes the lives of individuals, collects and tells stories about people's lives, and writes the narratives of an individual's experiences. The narrative typically focuses on studying a single person, gathering data through the collection of stories, reporting the individual experiences, and discussing the meaning of those experiences for the individual.

It can then be used to compare and contrast a number of stories to discover common themes and issues in participant's experiences.

<p>4. Proposed date                  a) of commencement: July, 2007                  b) of completion: October, 2008</p>
<p>5. Location(s) where research will be conducted (e.g. hospital, personal care home, participant home, etc.)</p> <p>Participant homes or a location of mutual choice (such as palliative care office, local community centre, nursing station)</p>
<p>6. Has study been approved by an accredited ethics board?                  Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>                  (If yes, include contact name &amp; information of Ethics Board)</p> <p>This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Research Ethics Secretariat at 474-7122, or e-mail to <a href="mailto:margaret_bowman@umanitoba.ca">margaret_bowman@umanitoba.ca</a>.</p>
<p>7. Has study been denied approval by an accredited ethics board?                  Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>                  (If yes, state why it was denied &amp; include contact name &amp; information of Ethics Board)</p>

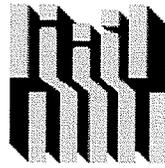
**For Office Use Only**

8. Does the research support RHA-Central Manitoba Inc. Board Ends and values statement? Yes \_\_\_\_\_ No \_\_\_\_\_  
(If no, please describe)

9. Resources Utilization Form (Exhibit ???) – has been completed by Researcher(s) or appropriate RHA staff  
Yes  
\_\_\_\_\_ No \_\_\_\_\_ N/A \_\_\_\_\_

10. Other comments:

**Interlake Regional Health Authority**



**INTERLAKE REGIONAL  
HEALTH AUTHORITY**

**REQUEST TO CONDUCT RESEARCH - EXTERNAL AGENCIES**

**IDENTIFICATION**

<b>Date:</b> July 10, 2007
<b>Name:</b> Sandra Taylor
<b>Address:</b>
<b>Phone Number: Work:</b> _____ <b>Home:</b> _____
<b>Email Address:</b>
<b>Title of Project:</b> Transcending Death by Living: Needs of Rural Manitoba Women Caregivers Providing Care for their Spouses (Common law or life partners) with Terminal Cancer at Home

<b>FOR STUDENTS ONLY</b>
<b>School/University/College:</b> University of Manitoba
<b>Faculty/Department:</b> Social Work
<b>Course Research is Required For:</b> Masters Thesis
<b>Course Instructor/Advisor:</b> Tuula Heinonen
<b>Ethical Approval Obtained From:</b> Psychology/Sociology Research Ethics Board
<b>Date:</b> June 18, 2007

If affiliated with the region, indicate site/facility:
<b>Please Note: A letter from the course instructor/advisor identifying the student and outlining the purpose of the project is required.</b>

<b>FOR ALL NON-STUDENT RESEARCHERS</b>	
Organization:	
Position Held:	
Supervisor (Name & Job Title):	
Ethical Approval Obtained From:	Date:
If affiliated with the region, indicate site/facility:	

**RESEARCH PROJECT (To Be Completed By All Applicants)**

<p><b>1. Short Description of Project (Attach Detailed Proposal):</b></p> <p><i>Please see attachments</i></p>
<p><b>2. Duration of Project:</b></p> <p>Anticipated Start Date: July 1, 2007                      Completion Date: October 2008</p>
<p><b>3. Plans for Publication:</b></p>

**a) Will research results be published? Y N**

**Indicate where and when, if known:** Dafoe Library at the University of Manitoba will have a complete copy of the thesis. Summary of findings will be provided to all participants and any participating Health Regions that request them.

**b) Will the IRHA or the facility/ program be identified in the report? Y N**

**c) You are required to submit a copy of the completed report to the region prior to publication.**

**4. What contact will you require with staff? With clients?**

I will need support from someone who has access to information about previous female clients offering palliative care at home. I am asking for about 4 letters to be sent out to people who fit the criteria I am working with in order that their confidentiality remains intact until they decide they want to participate in the project. If there is somewhere a poster can be placed for people to see who may fit the criteria, I ask the staff to do this as well.

Clients will be asked to participate in a 1 ½ to 2 hour interview with the researcher talking about their experiences of doing palliative care at home and what kinds of things they did to take care of themselves and what may have been or was helpful for their own health. *(Please see attached interview guide for sample questions).*

**5. What requirements will you have in the region/facility/site (ie. Supplies, equipment, space)?**

No supplies or equipment, unless there are a couple more clients the staff wishes to send out potential participant forms to. I will send along 4 copies and ask for those to be sent out. In the event a couple other potential participants are found, photocopying the couple page letter would be necessary.

In the event a woman does not want to interview in her home, space may be requested in your facility. If this is the case a small room to support two people for a couple hours to interview may be required.

**Sandra Taylor BSc, BSW, MTS**

\_\_\_\_\_

**Signature of Applicant**

**Signature of Faculty Advisor**

**(Students Only)**

**Approval Granted: \_\_\_\_\_**

**Request Denied: \_\_\_\_\_**

\_\_\_\_\_

\_\_\_\_\_

**Date**

**Signature of VP, Planning**

## Summary of Project

The purpose of this research study entitled *Transcending Death by Living: Needs of Rural Manitoba Women Caregivers Providing Care for their Spouses (Common Law/Life Partners) with Terminal Cancer at Home* is fourfold: 1) to understand the experience of women who cared for their dying spouses (common law/life partners) in rural Manitoba; 2) to determine what women caregivers needed in terms of caregiver supports in home palliative care; and 3) whether those supports were available and if so, from what source; and 4) what the quality of those supports were from the perspective of the female caregiver. Put another way, the central question is: What do rural women caregivers say were their support needs when they provided palliative care at home to their spouse (common law/life partner)? The hope is this study may be used as part of a continuum of research that tries to help health care professionals understand more fully the needs of the unpaid caregiver, and that public policies being made take more seriously the needs of women and incorporate their voices in policy decision making.

Using narrative research, the researcher describes the lives of individuals, collects and tells stories about people's lives, and writes the narratives of an individual's experiences. The narrative typically focuses on studying a single person, gathering data through the collection of stories, reporting the individual experiences, and discussing the meaning of those experiences for the individual. It can then be used to compare and

contrast a number of stories to discover common themes and issues in participant's experiences.

My intention is to conduct a single intense interview including several open-ended semi-structured questions with each participant. This interview is intended to take 1.5 – 2 hours. In the event this is not possible for some reason, the option of a second interview either in person or by telephone may be arranged. Depending on what information has been gathered in the first interview, a partial interview may be able to be analyzed and used in data analysis if a concluding interview is not possible to schedule. Interviews will be conducted at a location chosen by the participant and agreed to by the researcher. Possible locations may include participant homes, a local community centre (or church), the nursing station, or the palliative care office (if such exists). If a participant feels there is other information she wishes to add, she will be encouraged to contact the researcher either by phone or email and a subsequent interview or information exchange will occur either by phone or in person. Also a request for a subsequent interview will be sought in the event further clarification or other information is needed by the researcher.

### **Study Subjects**

My intent is to obtain data from six to eight women who provided palliative care in different rural settings within Manitoba. I will be targeting six health regions including Assiniboine, Central, South Eastman, North Eastman, Interlake, and Parkland. I am open to speaking with women of all backgrounds, including socioeconomic status, culture,

and sexual orientation as long as they are able to speak and understand English well. Because of the complexities associated with people living on reserves in Manitoba such as healthcare funding provided by the federal government perhaps leading to an even further lack of resources and many other compounding issues, I am excluding this population from my study. My hope is to include women who have provided palliative care between one and five years prior to the date of the interview thus offering a significant period for initial grief but a short enough time that detailed information may still be accessible.

Ringdal, Jordhoy, Ringdal, and Kaasa (2001) studied close family members of people who had died of cancer and found their grief and bereavement intensified slightly up to three months after the death, but then steadily declined up to 13 months post death. They found that beyond 13 months, although grief and bereavement continued, most people were back to feeling functional in their prior and new found roles. This supports the understanding then that a year allows women the time necessary to move through all the firsts that come after a death. By using five years post death as participation criteria, my hope is to offer enough time so the women can tell their stories, but not have so much time pass that details are lost, greatly re-interpreted, or significantly changed, or that women simply forgot what was or may have been helpful during the process of caregiving.

Participant recruitment will begin at the Manitoba Cancer Clinic where I will post the flyer identifying target groups desired and advertising the research. Professionals

such as palliative care team coordinators and church ministers or pastors in rural communities will be contacted asking for support in linking potential participants to the researcher. A letter for potential participants will be given to these professionals and they will be asked to give them to people meeting the research criteria. This allows potential participants the option to contact the researcher in the event they are interested, but does not give the researcher access to information about people who are not potentially interested in being a part of the research. A snowball approach will aid in creating sufficient numbers.

### **Informed Consent**

Forms for consent to participate will be completed before the beginning of the first interview. Each woman will have the opportunity to read the presented form and ask any questions necessary to understand it. If they prefer, the researcher will read and explain the form so they may still have the ability to participate. Signed consent forms will indicate an understanding of requirements and a willingness to engage in the process. Each participant will receive a copy of their signed consent form. As well participation needs to remain informed throughout the research process and participants will be encouraged to seek clarification or ask for new information throughout participation in the research.

## **Deception**

No deception will be used in the course of this research project. All subjects will be aware they are participating in a research study and informed consent will be obtained.

## **Feedback/Debriefing**

At the end of interviews, all of the data will be analyzed and compiled into a summary of findings. This summary will contain things such as quotes from participants as well as writings on consistent themes and any discrepancies found. A summary of the findings will be provided by the researcher to each participant by email, fax, or by mail. The preferred way of receiving the findings is requested at the bottom of the consent form. Participants have the choice to receive findings by supplying either an email address, fax number or mailing address.

As well, the summary of findings will be made available to women and organizations who request them. An oral defence will be held and is open to the public including people at the University of Manitoba. The final thesis will be provided to the University of Manitoba library.

## **Risks and Benefits**

There is minimal risk to participating in the study; however there is a possibility that during or after the interview emotions or issues may surface that the participant would like further support with. In the consent to participate form, Klinik's toll free

number (1-888-322-3019) has been clearly identified. That number can be accessed 24 hours a day. As well, when I know the location (i.e. town) of the participants, I will gather and provide information regarding any local counselling resources that may be available in their area.

## **Research Instruments**

The first instrument is a Call for Participant poster. All instruments are copied onto Faculty of Social Work letterhead.

## **Ethics**

Ethics approval is attached at the end of this document. The original is copied on University of Manitoba letterhead.

## ***North Eastman Regional Health Authority***

### **Summary of Project**

The purpose of this research study entitled *Transcending Death by Living: Needs of Rural Manitoba Women Caregivers Providing Care for their Spouses (Common Law/Life Partners) with Terminal Cancer at Home* is fourfold: 1) to understand the experience of women who cared for their dying spouses (common law/life partners) in rural Manitoba; 2) to determine what women caregivers needed in terms of caregiver supports in home palliative care; and 3) whether those supports were available and if so, from what source; and 4) what the quality of those supports were from the perspective of the female caregiver. Put another way, the central question is: What do rural women caregivers say were their support needs when they provided palliative care at home to their spouse (common law/life partner)? The hope is this study may be used as part of a continuum of research that tries to help health care professionals understand more fully the needs of the unpaid caregiver, and that public policies being made take more seriously the needs of women and incorporate their voices in policy decision making.

Using narrative research, the researcher describes the lives of individuals, collects and tells stories about people's lives, and writes the narratives of an individual's experiences. The narrative typically focuses on studying a single person, gathering data through the collection of stories, reporting the individual experiences, and discussing the meaning of those experiences for the individual. It can then be used to compare and

contrast a number of stories to discover common themes and issues in participant's experiences.

My intention is to conduct a single intense interview including several open-ended semi-structured questions with each participant. This interview is intended to take 1.5 – 2 hours. In the event this is not possible for some reason, the option of a second interview either in person or by telephone may be arranged. Depending on what information has been gathered in the first interview, a partial interview may be able to be analyzed and used in data analysis if a concluding interview is not possible to schedule. Interviews will be conducted at a location chosen by the participant and agreed to by the researcher. Possible locations may include participant homes, a local community centre (or church), the nursing station, or the palliative care office (if such exists). If a participant feels there is other information she wishes to add, she will be encouraged to contact the researcher either by phone or email and a subsequent interview or information exchange will occur either by phone or in person. Also a request for a subsequent interview will be sought in the event further clarification or other information is needed by the researcher.

### **Study Subjects**

My intent is to obtain data from six to eight women who provided palliative care in different rural settings within Manitoba. I will be targeting six health regions including Assiniboine, Central, South Eastman, North Eastman, Interlake, and Parkland. I am open to speaking with women of all backgrounds, including socioeconomic status, culture,

and sexual orientation as long as they are able to speak and understand English well. Because of the complexities associated with people living on reserves in Manitoba such as healthcare funding provided by the federal government perhaps leading to an even further lack of resources and many other compounding issues, I am excluding this population from my study. My hope is to include women who have provided palliative care between one and five years prior to the date of the interview thus offering a significant period for initial grief but a short enough time that detailed information may still be accessible.

Ringdal, Jordhoy, Ringdal, and Kaasa (2001) studied close family members of people who had died of cancer and found their grief and bereavement intensified slightly up to three months after the death, but then steadily declined up to 13 months post death. They found that beyond 13 months, although grief and bereavement continued, most people were back to feeling functional in their prior and new found roles. This supports the understanding then that a year allows women the time necessary to move through all the firsts that come after a death. By using five years post death as participation criteria, my hope is to offer enough time so the women can tell their stories, but not have so much time pass that details are lost, greatly re-interpreted, or significantly changed, or that women simply forgot what was or may have been helpful during the process of caregiving.

Participant recruitment will begin at the Manitoba Cancer Clinic where I will post the flyer identifying target groups desired and advertising the research. Professionals

such as palliative care team coordinators and church ministers or pastors in rural communities will be contacted asking for support in linking potential participants to the researcher. A letter for potential participants will be given to these professionals and they will be asked to give them to people meeting the research criteria. This allows potential participants the option to contact the researcher in the event they are interested, but does not give the researcher access to information about people who are not potentially interested in being a part of the research. A snowball approach will aid in creating sufficient numbers.

### **Informed Consent**

Forms for consent to participate will be completed before the beginning of the first interview. Each woman will have the opportunity to read the presented form and ask any questions necessary to understand it. If they prefer, the researcher will read and explain the form so they may still have the ability to participate. Signed consent forms will indicate an understanding of requirements and a willingness to engage in the process. Each participant will receive a copy of their signed consent form. As well participation needs to remain informed throughout the research process and participants will be encouraged to seek clarification or ask for new information throughout participation in the research.

## **Deception**

No deception will be used in the course of this research project. All subjects will be aware they are participating in a research study and informed consent will be obtained.

## **Feedback/Debriefing**

At the end of interviews, all of the data will be analyzed and compiled into a summary of findings. This summary will contain things such as quotes from participants as well as writings on consistent themes and any discrepancies found. A summary of the findings will be provided by the researcher to each participant by email, fax, or by mail. The preferred way of receiving the findings is requested at the bottom of the consent form. Participants have the choice to receive findings by supplying either an email address, fax number or mailing address.

As well, the summary of findings will be made available to women and organizations who request them. An oral defence will be held and is open to the public including people at the University of Manitoba. The final thesis will be provided to the University of Manitoba library.

## **Risks and Benefits**

There is minimal risk to participating in the study; however there is a possibility that during or after the interview emotions or issues may surface that the participant would like further support with. In the consent to participate form, Klinik's toll free

number (1-888-322-3019) has been clearly identified. That number can be accessed 24 hours a day. As well, when I know the location (i.e. town) of the participants, I will gather and provide information regarding any local counselling resources that may be available in their area.

## **Research Instruments**

The first instrument is a Call for Participant poster. All instruments are copied onto Faculty of Social Work letterhead.

## **Ethics**

Ethics approval is attached at the end of this document. The original is copied on University of Manitoba letterhead.

## **Appendix D**

### ***Professional Contact Letter***



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Worker@UManitoba.CA

**Transcending Death by Living: Needs of Rural Manitoba  
Women Caregivers Providing Care for their Spouses  
(common law/life partners) with Terminal Cancer at Home.**

Researcher: Sandra Taylor, BSc, BSW, MTS      Advisor: Tuula Heinonen, PhD  
MSW Candidate      Associate Professor  
Phone:      (Social Work)  
Email:      Phone 474-9543

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**Professional Contact Letter**

To Whom It May Concern:

My name is Sandi Taylor and for my Master's Thesis as a student for a Masters in Social Work degree, I am conducting narrative research to examine **the needs of rural Manitoba female spouses (common law/life partners) providing care to their partner at home in the terminal stages of cancer.** I am contacting you in the hope you can help me in my quest for participants for this research.

As a part of your position in the community, I understand you may have access to or know women who were primary caregivers at home while their partner was in the terminal stages of cancer. I am looking for 6-8 women who would be willing to participate in this research.

I have included in this package a letter to potential participants that I ask you to send out or give to any women who meet the following criteria.

- **A woman who lived in rural Manitoba when their spouse (common law/life partner) was ill.**

- **A woman who lived off-reserve.**
- **A woman who speaks and reads English.**
- **Had primary caregiving responsibility at home for their spouse (common law/life partner).**
- **A woman whose spouse (common law/life partner) died more than one year ago and less than six years ago.**
- **May be open to sharing their experiences.**
- **May be open to talking about supports and resources that they think are needed when providing care at home.**

By asking you to send letters to potential participants, confidentiality of all your clients remains intact. Women are free to contact me if they wish to participate, and only then will I learn of their situation. Those women who choose not to respond are assured I have no identifying information about them.

If you have any questions or concerns, please feel free to contact me at your earliest convenience at xxx-xxxx or email me at xxxxx@xxx.

I thank you for your time and consideration in assisting me with this recruitment work and I look forward to working with you as I move into this research project.

Sincerely,

Sandi Taylor

## **Appendix E**

### ***Introduction to Study for Potential Participants***



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

**Transcending Death by Living: Needs of Rural Manitoba  
Women Caregivers Providing Care for their Spouses  
(common law/life partners) with Terminal Cancer at Home.**

Researcher: Sandra Taylor, BSc, BSW, MTS    Advisor: Tuula Heinonen, PhD  
MSW Candidate    Associate Professor  
Phone:    (Social Work)  
Email:    Phone 474-9543

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**Introduction to Study for Potential Participants**

**Are you a rural woman who cared for your spouse (common law/life partner) at home in the terminal stages of his/her cancer?  
Would you like to share your experiences?**

To Whom It May Concern:

As part of my studies to obtain a Master of Social Work degree, I am conducting my Master's Thesis research to examine the needs of rural Manitoba female spouses (common law/life partners) providing care at home to their partner in the terminal stages of cancer. You have received this letter because the sender understands you have had this role for your partner who is now deceased. However, I want to assure you that your identity has not been revealed to me by the sender.

Participation in this study is completely voluntary. If you choose to decline to participate, there will be no negative consequences. For example, any services you currently or in the future may receive regarding the bereavement of your spouse (common law/life partner) will not be affected. Further you may choose to withdraw from the study or omit answering any question you are not comfortable with at any time without prejudice or consequences. If you should choose to participate in this study, there is minimal risk to your participation; however there is a possibility that during or after the interview emotions or issues may surface that you would like further support with. In this case, Klinik Community Health Centre has a toll free number (1-888-322-3019) that can

be accessed 24 hours a day where someone can offer you immediate phone support. As well, I will provide information regarding any local counselling resources that may be available in your area.

Your participation will remain confidential, within the limits of required reporting (e.g., child abuse and the duty to report). “Duty to report” refers to the understanding that researchers may be compelled by law to reveal information disclosed in interviews (such as threats of violence, commission of crimes and incidents of child abuse). This means the researcher is obligated to report information where there is a risk of harm to children or other persons.

Information received from participants will remain confidential. Pseudonyms will be assigned to each interview and only the researcher will have access to the connection between actual identity and pseudonyms. Identifying interview information will not be published, except as collective information and as part of the research study. However, it is possible that when the research report is written, you may be identified by some who know about your caregiving experience, for example others in your rural community.

In order to participate in this study, I am seeking women who had primary caregiving responsibility at home for their partner; lived in rural Manitoba when their spouse (common law/life partner) was ill; lived off-reserve; whose partner died more than one year ago but less than six years ago; and who would like the opportunity to share their experiences and would be open to talking about supports and resources that they think are needed when providing care at home.

As the primary caregiver, you had the major responsibility for the care of your spouse (common law/life partner) during the end stages of life. I would like the opportunity to meet with you and understand what it meant for you to be a caregiver and what you think are needed in terms of resources and support when providing care at home.

The interview will be approximately 1 ½ - 2 hours in length and will be done in person at a time and place convenient for you. I will ask you questions which you can choose to answer or decline. Questions asked will include the kinds of tasks you performed as a caregiver, including the most difficult and the most rewarding things. I will also ask about the supports and resources you received and whether more or alternative kinds of help would have been beneficial. With your consent, the interview will be tape-recorded.

Your responses will be treated confidentially and no identifying information will be shared with anyone else.

If you are willing to participate in this research project or would like more information, please phone me at your earliest convenience at xxx-xxxx.

I understand that talking about the death of a loved one may create emotion for you and your family, and I sincerely appreciate the time you have taken to consider this.

Sincerely,

Sandi Taylor

## **Appendix F**

### ***Telephone Screening Interview***

Hello, I understand you are calling me in response to my request for participants to a small research project I am doing for my Master of Social Work program. First I want to thank you so much for taking the time to respond because without people like you being willing to take the time to speak to me, I could not do this.

I am curious to know how you heard about this research project. I am trying to recruit people a couple of different ways and knowing helps me understand how the recruitment process is happening.

Let me tell you a little bit about this research project, why I am doing it, and what my hopes are.

- In 1999 my mom cared for my dad in the terminal stages of lung cancer at home and as I watched this take place, it struck me that there was not a lot of support (besides home care) offered to her to help her look after herself during this time. So I became curious whether there were other things available or not.
- According to Health Canada, more and more people are remaining at home for longer periods of time in the terminal stages of a disease. So I want to learn from women like you who have already had a primary caregiving role what it is you had or think would have been helpful during this time to help you continue caring for yourself and your spouse (common law or life partner) at home.

- So I am looking for 6-8 women who are willing to talk with me about their experiences of taking care of their spouse (common law or life partner) at home while he/she was in the palliative stage of their cancer.
- I have four purposes for this research: 1) to understand the experience of women caring for their dying spouses (common law or life partners) in rural Manitoba; 2) to determine what women caregivers need in terms of caregiver supports in home palliative care; and 3) whether those supports are available and if so, from what source; and 4) what the quality of those supports are from the perspective of the female caregiver.
- My hope is that as research in the area of palliative care continues, this study will be part of the mix of research that can help health care professionals understand more fully the needs of unpaid caregivers such as you and incorporate them into the palliative care programs as they continue to develop in rural Manitoba.

Does this sound like something you still might be interested in participating in?

**If yes:** That's wonderful, thank you. Is it alright if I ask you a few more questions so I can make sure you fit into the criteria for this study?

**If no:** That's just fine. I want to thank you anyway for taking the time to call me and find out more about this study. Take care of yourself and if you have any further questions you would like to ask me about this study and possibly participating, please feel free to contact me again. Bye.

### Screening questions

- Did your spouse (common law or life partner) die of cancer?
- Can you please tell me how long ago your spouse (common law or life partner) died (past away)? I am hoping to interview women who have been widowed between 1 and 5 years.
- Did you have primary responsibility for the daily care of your spouse (common law or life partner) while at home?
- Did you live in rural Manitoba while you cared for your spouse (common law or life partner) in one of the following health regions: Assiniboine, Central, South Eastman, North Eastman, Interlake, or Parkland?
- Did you live on a reserve while you cared for your spouse (common law or life partner)? **If asks why:** I am not interviewing people who lived on reserves because the needs in these communities are different than in other communities and it would be difficult and unfair to try and make any comparisons between on reserve and off reserve caregiving needs.
- Do you currently have anyone who you can talk to openly about issues surrounding your spouse's (common law or life partner's) death such as a close family member, friend, or counsellor? I ask this because if something were to come up during the interview, I want to know you have access to someone to talk to so you can continue to be supported even after the interview. If not, that's okay as I can bring with me some resources where you can get extra support if you need.

- Are you willing to share your experiences with me in a 1 ½ - 2 hour (audio taped) interview that will ask things like what it was like to care for your spouse (common law or life partner) at home, what kinds of things you did to look after yourself, what resources and supports you had, what resources and supports you found helpful and not helpful, and if you had the opportunity to tell health care providers what you would have liked what would that be? At the end of the project and once my thesis has been approved, the audio tapes will be destroyed so your identifying information and story will remain confidential.

**If fits into the study parameters:**

I would like to set up an in person interview with you at your earliest convenience if that is alright. I am willing to come out to your area so you do not have to travel. We can meet either at your home, or at another place that makes sense for you, like the community hall, or nursing station (hospital). What I need is a date that works for you and a time frame (morning or afternoon). I will bring with me everything else. You will need to sign a consent form before we begin and if you have access to email or fax and would like to see it ahead of time, I would be happy to email or fax it to you.

Do you have any other questions for me at this point? (answer whatever comes up). If you find you do at a later time, please do not hesitate to give me a call and I will be happy to answer anything further.

Again, thank you for doing this with me and I look forward to meeting with you and learning from your experiences.

**If doesn't fit into the study parameters:**

Unfortunately at this point, you don't fit into the criteria I have set for this study. (explain where they don't fit). However, if down the road (within four weeks), I need to expand my criteria, can I contact you again to set up an interview with you? Although my hope is to have enough women, I never know who may be willing and able to do this study with me and so my criteria may need to change. I still want to thank you for taking the time to contact me and if within four weeks I expand my criteria, I will contact you again. Do you have any questions for me at this point? If not then thanks again and take care of yourself. Bye.

## **Appendix G**

### ***Interview Guide***

**Demographic Data Outline.**

The demographic data outline and other information pages will be used by the researcher to organize demographic data. Some of the information will come out of the actual interview and if not all information is gathered through the interview, then the researcher will ask for any remaining information.

Person with Cancer		Caregiver	
Age at death		Age at spouse's death	
Sex		Employment	
Ethnicity		Ethnicity	
Religion		Religion	
Illness duration		Any issues regarding	
- From first diagnosis		your health while	
- From terminal stage		Caregiving?	
Type(s) of cancer			

**Other Information**

What area of Manitoba did you live while you were caring for your spouse (common law or life partner)?

\_\_\_\_\_

How long were the two of you together? \_\_\_\_\_

Were there other family members or friends present in the household on a daily basis?

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Were there other family members living in the community?

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Did you or your partner have affiliation(s) with community groups (such as Odd Fellows, Legion, Optimists, or Lions) prior to the illness?

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If yes, did these affiliation(s) continue during the illness? \_\_\_\_\_

Date of death \_\_\_\_\_

Place of death (home/hospital/other) \_\_\_\_\_

*Sample Questions for Open-ended Interview*

1. Please tell me the story of \_\_\_\_\_'s illness. How were you involved in the care?
  - What was it like to be a caregiver? (Caregiver can be defined as the person primarily responsible for the day to day care of the person with terminal cancer)
  - What were the positive and rewarding aspects of providing care?
  - What kinds of things did you do to look after yourself?
  - What were the most challenging aspects of providing care? What things did you have to learn? Were you offered ways to learn those things?
  - How did your family life change while \_\_\_\_\_ needed care?
  
2. There are many different kinds of support (formal – hospital, home care; and informal – friends, family) available for a person to draw on. Where did you get your support from?
  - What kinds of formal supports were offered to you? Did you utilize any of these? How did you decide what kinds of support to use and what not to?
  - What was your relationship like with other care providers such as doctors, nurses, community services/agencies (such as home care, social work, etc)? Was this different from previous experiences?
  - Thinking back to your time of caregiving, are there other supports you wished you had or that you think would have been helpful to have?

3. If you had the opportunity to tell social or health care policy makers what kinds of things are a must for supporting a female caregiver, what would you say to them?
  - What would you say to the formal caregivers (such as nurses, doctors, and social workers)?
  - What information would you want a person beginning the caregiving process to have in terms of what to expect, what to learn (or know), and what to ask for to take care of themselves?
  
4. Is there anything else you would like to add?

## **Appendix H**

### ***Support Information for Participants***

**Central Region Health Authority**Regional Health Authority  
Central Manitoba Inc.Office régional de la santé  
du Centre du Manitoba inc.**Resource Directory**

Nov-06

**MENTAL HEALTH OFFICES****Altona****Altona Mental Health**Altona Health Centre  
Box 660  
Altona MB R0G 0B0Phone: (204) 324-6411  
Fax: (204) 324-8482  
E-mail: jpetkau@rha-central.mb.ca*Johanna Rempel-Petkau, CMH Worker – C&A***Boundary Trails Health Centre****Mental Health**c/o Boundary Trails Health Centre  
Box 2000, Station Main  
Winkler MB R6W 4B8

Fax: (204) 331-8831

*Guido Faralli, CMH Worker-C&A**Karen Street/Heidi Tremblay, Mental Health Liaison urse*Phone: (204) 331-8825  
Phone: (204) 331-8920**Carman****Carman Mental Health**Box 1442  
Carman MB R0G 0J0Phone: (204) 745-3745  
Fax: (204) 745-3600*Cheryl Dyck, CMH Worker – Adult**Kerwin Bastler, CMH Worker*

E-mail: cdyck@rha-central.mb.ca

**Crystal City****Crystal City Mental Health**C/o Rock Lake Health District Hospital  
Box 130, 135 Machray Avenue  
Crystal City, MB R0K 0N0Phone: (204) 873-2483  
Fax:  
E-mail: dpeers@rha-central.mb.ca*Daphne Andrew-Peers, Child & Adolescent/Adult Mental Health Services***Gladstone****Gladstone Mental Health**c/o Seven Regions Health Centre  
Box 1000  
Gladstone MB R0J 0T0Phone: (204) 385-3088  
Fax: (204) 385-2663  
E-mail: cbjarnarson@rha-central.mb.ca*Debbie S. Bjarnarson, CMH Worker-Adult***MacGregor****MacGregor Mental Health**Box 123  
MacGregor MB R0H 0R0Phone: (204) 685-2400  
Fax: (204) 685-2938  
E-mail: cbjarnarson@rha-central.mb.ca*Debbie S. Bjarnarson, CMH Worker-Adult***Manitou****Manitou Mental Health**c/o Pembina Manitou Health Centre  
Box 129  
Manitou MB R0G 1G0Phone: (204) 242-2678  
Fax: (204) 242-3463  
E-mail: dpeers@rha-central.mb.ca*Daphne Andrew Peers, CMH Worker-Adult*

**MENTAL HEALTH OFFICES****Miami****Miami Mental Health**Box 334  
Miami MB R0G 1H0Phone: (204) 435-2297  
Fax: (204) 435-2768  
E-mail: bcallum@rha-central.mb.ca*Barb Callum, CMH Worker-C&A***Morris****Morris Mental Health**c/o Morris General Hospital  
Box 519, 215 Railroad Ave. E.  
Morris MB R0G 1K0

Fax: (204) 746-8842

*Melonee Aldred, intensive Case Management maldred@rha-central.mb.ca*  
*Kim Toews, CMH Worker-C&A ktoews@rha-central.mb.ca*  
*Evelyn Bartel, CMH Worker-Adult ebartel@rha-central.mb.ca*Phone: (204) 746-6222  
Phone: (204) 746-8772  
Phone: (204) 746-8079**Notre Dame de Lourdes****Notre Dame Mental Health**Box 123  
Notre Dame de Lourdes MB R0G 1M0Phone: (204) 248-2248  
Fax: (204) 248-2087  
E-mail: dpeers@rha-central.mb.ca*Daphne Andrew Peers, CMH Worker-Adult***Child & Adolescent Psychiatrist**Box 220, 134 Notre Dame Ave.  
Notre Dame de Lourdes MB R0G 1M0Phone: (204) 248-2665  
Fax: (204) 248-2670*Dr. Barbara Comte, C&A Psychiatrist*  
*Vacant, Admin Support (Mon, Wed + Fri a.m.)*E-mail: bcomte@rha-central.mb.ca  
E-mail: xxx@rha-central.mb.ca**Portage la Prairie****Portage la Prairie Child & Adolescent Mental Health**25 Tupper Street N.  
Portage la Prairie MB R1N 3K1Phone: (204) 239-3131  
Fax: (204) 239-3148*Christine Longford, CMH Worker - C & A Email: clongford@rha-central.mb.ca*  
*Pat Jamieson, CMH Worker - C & A Email: pjamieson@rha-central.mb.ca*  
*Jackie Trotter, Admin Support Email: jtrotter@rha-central.mb.ca*Phone: (204) 239-3125  
Phone: (204) 239-3466  
Phone: (204) 239-3131**Portage la Prairie Community Mental Health**C/o Portage District General Hospital  
524 - 5<sup>th</sup> St., SE  
Portage la Prairie MB R1N 3A8Phone: (204) 239-2320  
Fax: (204) 239-0451*Bev Gradidge, Client Services Manager - Psychosocial Programs Email: bgradidge@rha-central.mb.ca*

Phone: (204) 239-2330

*Bob Crossman, CMH Intake Worker Email: bcrossman@rha-central.mb.ca*  
*Dartene MacClay, CMH Worker - Geriatric Email: bjamieson@rha-central.mb.ca*  
*Les Bowen, CMH Worker - Adult Email: lbowen@rha-central.mb.ca*  
*Teresa Houston, CMH Worker - ICM Email: thouston@rha-central.mb.ca*  
*Jane Park, CMH Worker - Adult Email: jpark@rha-central.mb.ca*  
*Heather Nachbauer, CMH Worker - Adult Email: hnauchbauer@rha-central.mb.ca*Phone: (204) 239-3000  
Phone: (204) 239-2307  
Phone: (204) 239-2312  
Phone: (204) 239-2314  
Phone: (204) 239-2313  
Phone: (204) 239-2309*Charles Grégoire, CMH Worker-ICM Email: cgregoire@rha-central.mb.ca*  
*John Abbors, Worker-ICM Email: jabbors@rha-central.mb.ca*Phone: (204) 239-2318  
Phone: (204) 239-2317  
Phone: (204) 239-2319E-mail updates to [kcrocker@rha-central.mb.ca](mailto:kcrocker@rha-central.mb.ca)



**MENTAL HEALTH OFFICES**

<i>Vacant, OT</i>	Phone:	(204) 239-2308
<i>Dave Cook, Mental Health Liaison Nurse Email: dcook@rha-central.mb.ca</i>		
<i>Jeff Hunter, Employment &amp; Housing Couns. Email: jehunter@rha-central.mb.ca</i>	Phone:	(204) 239-2320
<i>Carol Schneider, Admin Assist. Email: cschneider@rha-central.mb.ca</i>		
<b>Karen Devine Safe House</b> 159-5th Street S.E. Portage la Prairie MB R1N 1H4	Phone: Fax: E-mail:	(204) 239-5332 (204) 239-0551 jehunter@rha-central.mb.ca
<i>Jeff Hunter, Supervisor</i>		
<b>Mental Health Crisis Service NORTH (after office hours)</b>	Phone: Fax: E-mail:	(204) 239-2330 (204) 239-0451 bgradidge@rha-central.mb.ca
<i>Bev Gradidge, Supervisor</i>		
<b>Mental Health Crisis Service SOUTH (after office hours)</b>	Phone: Fax: E-mail:	(204) 239-2330 (204) 239-0451 bgradidge@rha-central.mb.ca
<i>Bev Gradidge, Supervisor</i>		

***Interlake Region Health Authority*****Mental Health Crisis Services**

Crisis Stabilization Unit	482-5361 (or Emergency Department of local hospital)
Mobile Crisis Team	482-5376

**Community Health Offices**

Provide a full range of health services such as public health, mental health and home care to all residents within the Interlake region. These services, and their supports, are provided on a local and regional basis. For more information or to access services, please contact your local Community Health Office.

Arborg Community Health Office	376-5559
Ashern Community Health Office	768-2585
Eriksdale Community Health Office	739-2161
Fisher Branch Community Health Office	372-8703
Gimli Community Health Office	642-4595
Lundar Community Health Office	762-5469
Riverton Community Health Office	378-2460
Selkirk Community Health Office	785-7715
St. Laurent Community Health Office	646-2504
Stonewall Community Health Office	467-4400
Teulon Community Health Office	886-4065

Interlake RHA regional programs may be accessed directly or through your local community health office.

**North Eastman Region Health Authority**

**Mental Health Manager**

24 Aberdeen Avenue

P.O. Box 339

Pinawa, MB R0E 1L0

Phone: 204-753-3124

Fax: 753-2015

Pager: 933 4095

Email: [sbissonnette@neha.mb.ca](mailto:sbissonnette@neha.mb.ca)

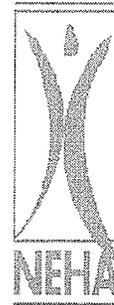


NEHA Corporate Office  
W.B. Lewis Centre  
24 Aberdeen Avenue / P.O. Box 339  
Pinawa, MB R0E 1L0  
Tel. (204) 753-2012  
Fax (204) 753-2015  
Toll-Free 1-877-753-2012  
email: [neha@neha.mb.ca](mailto:neha@neha.mb.ca)

Revised: January 2007

**MENTAL HEALTH  
SERVICES**

**NORTH EASTMAN HEALTH ASSOCIATION**



*"Working together to empower individuals,  
families and communities to pursue  
optimum health through  
healthy lifestyles."*

**OVERVIEW**

The North Eastman Community Mental Health Program is community based throughout the region

Services are available for people with emotional and psychiatric problems and mental illness.

Multidisciplinary teams of Community Mental Health professionals are available. Consultation is available with psychiatry and psychology.

**MENTAL HEALTH INTAKE & URGENT CARE SERVICES**

Provides intake assessments, urgent care services, education and resource information, and linkage to mental health or other services according to the reason for referral.

P.O. Box 28  
Oakbank, Manitoba R0E 1J0

Phone: 1-204-444-5057  
Cell: 1-204-645-3230  
Fax: 1-204-444-5056

Hours of Work: Monday to Friday 9:30 am to 5:30 pm.

**CHILD AND ADOLESCENT**

Provides assessment, treatment, educational and referral services to children, adolescents and their families.

Beausejour	Oakbank	Lac du Bonnet	Pine Falls
1-204-268-7483	1-204-444-6118	1-204-345-1231	1-204-367-5417

**ADULT MENTAL HEALTH**

Provides assessment, treatment, educational and referral service for adults.

Beausejour	Lac du Bonnet
1-204-268-7484	1-204-345-1211
Pine Falls	Whitemouth
1-204-367-5407	1-204-348-4614
Oakbank	
1-204-444-6117	

**RELATIONAL THERAPY SERVICES**

Provides relational therapy on such issues as communication, parenting, dealing with separation and divorce, stepfamilies, anger management, grief and loss, domestic abuse, sexual abuse, and chronic illness.

1-204-268-7492 / 1-204-367-5409

**MENTAL HEALTH SERVICES FOR THE ELDERLY**

Provides assessment, treatment, consultation and referral services and education resources for caregivers and families.

1-204-268-7481 / 1-204-268-7480 / 1-204-268-7486

**INTENSIVE CASE MANAGEMENT**

Provides psychosocial rehabilitation services to adults with severe and persistent psychiatric disabilities.

1-204-268-7482

**HOUSING AND PROCTOR SERVICES**

Provides housing and support options for people with psychiatric disabilities.

1-204-444-6129

**CRISIS SERVICES**

Mobile Crisis Unit

Specializes in crisis intervention and outreach services.

2:00 pm - 2:00 am (7 days a week)

1-204-482-5376 1-866-427-8628

Stabilization Unit

Provides an 8 bed residential unit for adolescents 15 years and older and adults in psychiatric crisis.

448 Queen Ave., Selkirk, MB

1-204-482-5361 1-866-427-8628

Community Trauma Postvention

Provides early intervention and education to communities affected by critical incidents/traumatic events, crisis or disasters to minimize long-term effects.

24 Hours

1-204-482-5361 1-866-427-8628

**MENTAL HEALTH SELF-HELP GROUPS**

Provides information, referral, public education, peer and family education and support.

Anxiety Disorders  
Association of Manitoba  
1-204-345-8511

Canadian Mental  
Health Association  
1-204-444-4691

Manitoba Schizophrenia Society  
1-204-371-0824

Mood Disorders Association  
of Manitoba  
1-204-326-3623

**Appendix I**

***Ethics Approval Form***



UNIVERSITY  
OF MANITOBA

OFFICE OF RESEARCH  
SERVICES

Office of the Vice-President (Research)

**APPROVAL CERTIFICATE**

CTC Building  
208 - 194 Dufour Road  
Winnipeg, MB R3T 2N2  
Fax (204) 269-7173  
www.umanitoba.ca/research

18 June 2007

**TO:** Sandra Taylor (Advisor T. Heinonen)  
Principal Investigator

**FROM:** Bruce Tefft, Chair *Bruce Tefft*  
Psychology/Sociology Research Ethics Board (PSREB)

**Re:** Protocol #P2007:052  
"Transcending Death by Living: Needs of Rural Manitoba Women  
Caregivers providing Care for their Spouses with Terminal Cancer at  
Home"

Please be advised that your above-referenced protocol, as revised, has received human ethics approval by the **Psychology/Sociology Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval has been issued based on your agreement with the change(s) to your original protocol required by the PSREB. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval: otherwise the account will be locked.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**

*Bringing Research to Life*

## **Appendix J**

### ***Consent to Participate***



Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

**Transcending Death by Living: Needs of Rural Manitoba  
Women Caregivers Providing Care for their Spouses  
(common law/life partners) with Terminal Cancer at Home.**

Researcher: Sandra Taylor, BSc, BSW, MTS      Advisor: Tuula Heinonen, PhD  
MSW Candidate      Associate Professor  
Phone:      (Social Work)  
Email:      Phone 474-9543

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**Consent to Participate**

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study involves participating in an interview regarding your experience as a female spouse (common law/life partner) caring for your partner at home through his/her terminal cancer illness. The intent of this research study is fourfold: 1) to understand the experience of women caring for their dying spouses (common law/life partners) in rural Manitoba; 2) to determine what women caregivers need in terms of caregiver supports in home palliative care; and 3) whether those supports are available and if so, from what source; and 4) what the quality of those supports are from the perspective of the female caregiver. The hope is this study may be used as part of a continuum of research that tries to help health care professionals (especially social workers) understand more fully the

needs of the unpaid caregiver, and that public policies being made will take seriously the needs of women and incorporate their voices in social and health care policy decision making.

Sandi Taylor, a graduate social work student at the University of Manitoba, will conduct the study. As a researcher, I am under the supervision of the Faculty of Social Work. The research study will normally be in the form of one interview that will take approximately 1.5 – 2 hours. It will consist of asking some questions about your experience as a caregiver. I am interested in hearing what it was like to be a caregiver; what you found as positive and challenging aspects of caregiving; and what kinds of things you did to look after yourself. I am also interested in the formal and informal help you may have received for yourself. Where did you receive support from; what types of formal supports were offered to you; and what was your relationship with other formal care providers (such as doctors and nurses). Finally, I will be asking for your suggestions about what other resources or supports may have been helpful to you during your time as primary caregiver for your spouse (common law/life partner) as well as what would be helpful in your opinion for social or health care policy makers to know about what kinds of things must be in place to adequately support a female caregiver.

The researcher will audiotape the interviews to improve accuracy. At the conclusion of the study and with the granting of the researcher's degree, audiotapes will be erased and shred and any other identifying information will be destroyed. This will happen by December, 2008.

There is minimal risk to participating in the study; however there is a possibility that during or after the interview emotions or issues may surface that you would like further support with. In this case, Klinik Community Health Centre has a toll free number (1-888-322-3019) that can be accessed 24 hours a day for immediate phone support. As well, I will provide information regarding any local counselling resources that may be available in your area.

Your participation will remain confidential, within the limits of required reporting (e.g., child abuse and the duty to report). “Duty to report” refers to the understanding that researchers may be compelled by law to reveal information disclosed in interviews (such as threats of violence, commission of crimes and incidents of child abuse). This means the researcher is obligated to report information where there is a risk of harm to children or other persons.

Information received from participants will remain confidential. Pseudonyms will be assigned to each interview and only the researcher will have access to the connection between actual identity and pseudonyms. Identifying interview information will not be published, except as collective information and as part of the research study. However, it is possible that when the research report is written, you may be identified by some who know about your caregiving experience, for example others in your rural community.

Participation in this study is completely voluntary. Withdrawal from the study at any time will not result in any punitive or negative consequences. There will be no form of remuneration offered to participants of this study. However, your participation in this study will add to knowledge about women caregivers’ needs. A summary of the findings

will be provided to each participant by email, fax, or by mail by October, 2008. As well, analysis of the data will be made available to women and organizations, who request them after October, 2008. An oral defence will be held and is open to the public and people at the University of Manitoba. The final thesis will be provided to the University of Manitoba library.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

**Principal Investigator:**                      **Sandi Taylor (204) xxx-xxxx and**

**Advisor:**    **Tuula Heinonen (204) 474-9543**

This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Research Ethics Secretariat at 474-7122, or e-mail to [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.

I have read this form, have had the opportunity to ask the researcher any question I have about the research, understand what my participation in the study entails, and am

willing to participate. My signature indicates my agreement and consent to be involved in this study.

---

Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

Are you interested in receiving a summary of my findings? To be provided by October, 2008.

\_\_\_\_\_yes      \_\_\_\_\_no

If yes, how would you like to receive these? Please choose one.

\_\_\_\_\_ **email**      Please provide your email address. \_\_\_\_\_

\_\_\_\_\_ **fax**      Please provide a fax number. \_\_\_\_\_

\_\_\_\_\_ **postal mail**      Please provide your complete mailing address.

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## **Appendix K**

### ***What is Cancer?***

Cancer is a disease that starts in our cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

Cells can form lumps or tumours, or can spread to through the bloodstream and lymphatic system to other parts of the body.

Tumours can be either *benign* (non-cancerous) or *malignant* (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening.

Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called *metastases*.

Cancers are named after the part of the body where they start. For example, cancer that starts in the bladder but spreads to the lung is called bladder cancer with lung metastases

(Reproduced under the permission of the Canadian Cancer Society, June 4, 2008 from What is Cancer?, (2008). Retrieved January 8, 2008 from [http://www.cancer.ca/ccs/internet/standard/0,3182,3331\\_562847522\\_langId-en,00.html](http://www.cancer.ca/ccs/internet/standard/0,3182,3331_562847522_langId-en,00.html)).

## *Types of Cancers*

### *Liver*

Liver cancer starts in the cells, bile ducts, blood vessels or connective tissue of the liver. Other types of cancer can spread to the liver (known as liver metastasis). It is estimated that 1,350 new cases of liver cancer will be diagnosed in Canada in 2007.

**Risks:** Risk factors may increase a person's chance of developing liver cancer. The factors that increase the risk of developing liver cancer include:

- infection with hepatitis B virus (HBV) or hepatitis C virus (HCV)
- aflatoxins (toxins from a fungus that lives in the soil and grows on foods)
- excessive alcohol use, usually by causing cirrhosis
- cirrhosis of the liver (a type of liver disease) as a result of alcohol use or infection

**Early detection:** *Early detection* means finding a cancer or precancerous condition at an early stage. In most cases, finding cancer early increases the chances of successful treatment.

There is no screening test for liver cancer. Therefore, recognizing symptoms and getting regular checkups are the best ways to detect liver cancer early. The sooner signs and symptoms are reported, the sooner a doctor can diagnose and treat the cancer.

People who have a higher than average risk for liver cancer should discuss an individual plan for testing with their doctor. Their doctor may suggest they have a blood test for the tumour marker alpha-fetoprotein (AFP) or an ultrasound of the liver.

**Signs and symptoms:** Other health conditions can have the same signs and symptoms as liver cancer, so having any of the following symptoms does not necessarily mean a person has cancer. However, it is important to see a doctor about:

- a lump on the right side of the body, just below the rib cage
- pain
  - in the right, upper abdomen
  - around the right shoulder blade
- loss of appetite
- nausea
- weight loss
- fatigue

**Diagnosis:** Diagnostic tests will be done if the signs and symptoms of liver cancer are present or if the doctor suspects liver cancer. Tests may include:

- complete physical examination
- laboratory tests
- imaging tests
- biopsy

Additional tests, such as x-rays, ultrasounds and scans, may be done to determine the stage (how far the disease has progressed).

**Pathology and staging:** When liver cancer has been diagnosed, tests will be done to find out:

- the type of liver cancer - The most common form of liver cancer (hepatocellular carcinoma) accounts for over 90% of liver tumours.
- the stage of the cancer (how far the cancer has progressed) - The stage is based on the tumour size and whether or not the cancer is in any lymph nodes or has spread to other areas of the body.
- the grade of the tumour (how abnormal the cancer cells look and behave)

Some of the most common sites where liver cancer can spread include the:

- portal vein (carries blood to the liver from the digestive system)
- hepatic veins (drain blood from the liver)

- regional lymph nodes
- diaphragm

Other types of cancer can spread to the liver. When this happens, the cancer is not considered to be liver cancer. Instead, it is a metastasis of the original cancer to the liver.

A person's prognosis depends on:

- grade of the tumour (the difference in appearance and function of cancer cells compared to normal cells)
- size of the tumour
- stage of tumour
- underlying liver disease

**Treatment:** Each person with liver cancer will have a treatment plan designed for them by their healthcare team. The team will recommend treatment options based on the specific characteristics of the cancer and the unique needs of the person. A treatment plan for liver cancer may include one or more of the following:

- surgery
  - partial hepatectomy – part of the liver is removed
  - laparoscopic resection – small tumours on the surface of the liver are removed
  - total hepatectomy and liver transplant – the whole liver is removed and replaced with a donor liver
- cryosurgery
  - destroys cancer cells by freezing them
  - may be used to treat tumours that cannot be removed by surgery
- radiofrequency ablation
  - uses a high-frequency electrical current to destroy cancer cells
  - may be used to treat tumours that cannot be removed by surgery
- percutaneous injection
- injection of a substance into the tumour to destroy cancer cells
- chemotherapy
  - usually doxorubicin or combinations of drugs that include doxorubicin
  - methods of giving the chemotherapy are:

- systemic (affecting the whole body)
- regional (affecting a specific part of the body)
- chemoembolization (blocks blood supply to a tumour and then delivers chemotherapy directly into the tumour mass)
- radiation therapy
- sometimes used to relieve pain and control the symptoms of advanced liver cancer

## ***Lung***

Lung cancer starts in the lung tissue. It can occur in both men and women.

It is estimated that 23,300 new cases of lung cancer will be diagnosed in Canada in 2007.

**Risks:** Risk factors may increase a person's chance of developing lung cancer. The most important risk factor for developing lung cancer is smoking. Most lung cancers are caused by smoking. Other risk factors include:

- exposure to cancer causing substances (carcinogens) in the workplace
- exposure to environmental carcinogens
- disease of the lung, particularly diseases that cause scarring or fibrosis of the lungs

Most lung cancers are caused by smoking so the most effective way to reduce the risk of developing lung cancer is not smoking and avoiding second hand smoke. No amount of tobacco is safe.

**Screening:** Screening methods for lung cancer are currently not available. To date, there are no recommended screening tests that are safe (repeated x-rays) and reliable (testing sputum for cancer cells).

**Signs and symptoms:** Signs and symptoms of lung cancer may include:

- cough
- breathing problems
- changes in phlegm (sputum)
- lung infection (pneumonia)

- hoarseness
- hiccups
- chest pain
- pleural effusion
- development of certain syndromes:
  - Pancoast syndrome
  - Horner's syndrome
  - superior vena cava syndrome

**Diagnosis:** Diagnostic tests will be done if signs and symptoms are present. Tests may include:

- complete physical examination
- medical history
- blood tests
- chest x-ray
- endoscopy
- biopsy
- additional x-rays and scans may be done to determine the extent (stage) of the cancer

**Pathology and staging:** Pathology tests will be done once lung cancer has been diagnosed to determine:

- the type of lung cancer
- the extent (stage) of lung cancer
- the aggressiveness (grade) of lung cancer
- These test results will help the doctor determine the best treatment.

**Treatment:** Treatment plans are designed to meet the unique needs of each person with cancer and the characteristics of their cancer (stage, grade, location).

Treatment for lung cancer may include one or more of:

- surgery
- chemotherapy
- radiation therapy
- laser therapy
- photodynamic therapy

## ***Melanoma***

Melanoma starts in the cells that produce melanin called melanocytes. Melanin is what gives colour to our skin, hair and eyes. Melanin is heavily concentrated in moles. Melanocytes are found in the deeper layer of the epidermis. A cancer of the skin occurs when a melanocyte grows uncontrollably and develops into a tumour. Melanoma can develop from or near a mole, or in tissue not different from surrounding skin.

Melanoma is most frequently found on the back of men and on the back and legs of women. However, melanoma can develop anywhere on the body, including the head and neck. Melanoma is the most serious type of skin cancer.

It is estimated that 4600 new cases of melanoma will be diagnosed in Canada in 2007.

**Risks:** Risk factors may increase a person's chance of developing melanoma. The factors that increase the risk of developing melanoma include:

- sun and ultraviolet radiation
- atypical moles
- familial atypical mole syndrome
- more than 50 moles
- light-coloured skin, eyes and hair
- giant congenital melanocytic nevi
- personal history of skin cancer
- family history of skin cancer
- weakened immune system
- history of severe sunburns and blistering

**Early detection:** Early detection means finding a cancer or precancerous condition at an early stage. In most cases, finding cancer early increases the chances of successful treatment.

Recognizing symptoms and getting regular checkups are the best ways to detect melanoma. The sooner symptoms are reported, the sooner a doctor can diagnose and treat the cancer. Learning what to look for and checking the skin regularly can help find most skin cancers early enough to be cured.

People who are at higher than average risk for melanoma, such as those with a strong family history of melanoma (2 or more first-degree relatives with the disease), familial atypical nevus syndrome should talk to their doctor about a personal plan for testing.

**Signs and symptoms:** Other health conditions can have the same signs and symptoms as melanoma, so having any of the following symptoms does not necessarily mean a person has cancer. However, it is important to see a doctor about:

A mole that changes in:

- size
- shape
- colour
- surface
- sensation
- texture
- surrounding skin

**Diagnosis:** Diagnostic tests will be done if the signs and symptoms of melanoma are present, or if the doctor suspects melanoma. Tests may include:

- complete physical examination
- biopsy

Additional x-rays, scans and other tests may be done to determine the stage (how far the disease has progressed).

**Pathology and staging:** When melanoma has been diagnosed, tests will be done to find out:

- the type of melanoma
  - Superficial spreading melanoma, nodular melanoma, lentigo maligna melanoma and acral lentiginous melanoma make up 90% of all diagnosed malignant melanomas. Superficial spreading melanoma is the most common type and represents 70% of these tumours.

- the stage of the cancer (how far the cancer has progressed)
  - The stage is based on the tumour size, and whether or not the cancer is in any lymph nodes or has spread to other areas of the body.
  - Melanomas can be microstaged by measuring the vertical thickness of the tumour and/or the anatomic level of local invasion. Breslow's classification involves determining the vertical thickness of the melanoma in millimetres. Clark's classification describes how deeply the melanoma penetrates into the skin. It does not measure the tumour.
- the grade of the tumour (how abnormal the cancer cells look and behave)

Some of the most common sites where melanoma can spread include the:

- lymph nodes
- skin
- lungs
- brain
- spinal cord
- liver
- bone

A person's prognosis depends on:

- the stage of the cancer (lymph node involvement and burden)
- tumour thickness, ulceration and depth of invasion
- a person's age
- anatomical site
- performance status

This information is used to plan the best treatment for each person with melanoma.

**Treatment:** Each person with melanoma will have a treatment plan designed for them by their healthcare team. The team will recommend treatment options based on the specific characteristics of the cancer and the unique needs of the person. A treatment plan for melanoma may include one or more of the following:

- surgery

- Simple excision is used to remove the tumour.
- Re-excision is used after biopsy of a confirmed melanoma.
- Amputation may be necessary to treat a melanoma on the fingers, toes or nails.
- Skin graft or flap is sometimes necessary to close a wound after removal of a large melanoma.
- Sentinel lymph node biopsy is used to determine whether the melanoma has spread to the first lymph node.
- Lymph node dissection removes all the lymph nodes in the area near the tumour.
- Surgery for metastatic disease is considered for a person with a limited number of brain metastases to relieve symptoms and to help improve quality of life.
- chemotherapy
  - Chemotherapy may be used after surgery.
  - Chemotherapy may be used to relieve pain or to control the symptoms of advanced melanoma.
- regional chemotherapy
  - Regional chemotherapy can be used to treat melanoma that has spread directly to an arm or leg.
- radiation therapy
  - External beam radiation therapy is often used in many stages of the treatment.
- biological therapy
  - Biological therapy can be used following surgery or for recurrent disease.

### ***Non-Hodgkin Lymphoma***

Non-Hodgkin's lymphoma (NHL) starts in a type of white blood cell called a lymphocyte. There are two types of lymphocytes: B-cells (B-lymphocytes) and T-cells (T-lymphocytes).

Lymphomas occur in the lymphatic system and can develop wherever lymphocytes travel.

Non-Hodgkin's lymphoma differs from Hodgkin's lymphoma by:

- how the cells look under the microscope

- the presence of Reed-Sternberg cells in Hodgkin's lymphoma
- how the cells behave
- how the two types of lymphoma are treated

It is estimated that 6,800 new cases of non-Hodgkin's lymphoma will be diagnosed in Canada in 2007.

**Risks:** Risk factors may increase a person's chance of developing non-Hodgkin's lymphoma. The main factors that increase the risk of developing NHL are:

- growing older
- gender - men are at higher risk
- weakened immune system due to
  - immunosuppressant drugs
  - autoimmune disorders
  - immunodeficiency disorders
  - HIV/AIDS
- viral infections
- prolonged exposure to chemicals such as pesticides, herbicides, solvents or fertilizers
- previous chemotherapy or radiation therapy
- genetics

**Screening:** Screening is a way of detecting cancer early - before any signs and symptoms are noticed - with a test or examination.

Screening tests for non-Hodgkin's lymphoma are not currently available.

**Signs and symptoms:** Signs and symptoms of non-Hodgkin's lymphoma can also be caused by other health conditions, and do not necessarily mean a person has cancer. It is important to see a doctor about any of the following:

- enlarged, usually painless lymph nodes in the neck, armpit or groin
- unexplained weight loss
- excessive sweating at night
- unexplained fever
- general feeling of unwellness
- fatigue

**Diagnosis:** Diagnostic tests will be done if the signs and symptoms of non-Hodgkin's lymphoma are present, or if the doctor suspects NHL. Tests may include:

- complete physical examination
- laboratory tests
- imaging tests
- biopsy
- other tests to determine the extent (stage) of the disease

**Pathology and staging:** When non-Hodgkin's lymphoma has been diagnosed, other tests will be done to find out:

- the type of non-Hodgkin's lymphoma
  - B-cell lymphoma
  - T-cell lymphoma
- how far the cancer has spread (stage)
- the behaviour of the tumour
  - indolent
  - aggressive
- how well the cancer may respond to treatment (prognostic factors), based on
  - age
  - performance status
  - lactate dehydrogenase levels
  - stage of the disease
  - presence of extranodal disease

This information is used to plan the best treatment for each person with NHL.

**Treatment:** Each person with non-Hodgkin's lymphoma will have a treatment plan designed for them by their healthcare team. The team will recommend treatment options based on the specific characteristics of the cancer and the unique needs of the person with cancer. A treatment plan for NHL may include one or more of the following:

- chemotherapy

- single-agent drugs including chlorambucil (Leukeran) and fludarabine (Fludara)
- combination chemotherapy, usually CHOP (cyclophosphamide, doxorubicin [Adriamycin], vincristine [Oncovin] and prednisone)
- radiation therapy
  - on its own to treat localized areas of lymphoma
  - with chemotherapy as part of a combination treatment package
- biological therapy
  - involves the body's own immune system to fight cancer or lessen the side effects associated with some cancer treatments. For NHL, biological therapy may include rituximab (Rituxan) or alemtuzumab (Campath).
- stem cell transplantation
  - if the cancer has returned after first-line therapy
- watchful waiting
  - when the disease is progressing very slowly, there are no symptoms, and it is considered best to wait to begin chemotherapy or radiation therapy until necessary

(Reproduced under the permission of the Canadian Cancer Society, June 4, 2008 from Canadian Cancer Encyclopedia – Type of Cancer, (2006). Retrieved January 8, 2008 from <http://info.cancer.ca/E/CCE/cceexplorer.asp?tocid=25>)