

The Lived Experiences of Women Providing Care to Spouses Who are in
Long Term Care

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Dedication

This Thesis is dedicated to my mom, Elsie May Vezza, who did not live long enough to see its completion, but who believed in and inspired this journey.

CHAPTER ONE: INTRODUCTION

The British Columbia Association of Social Workers accepts the World Health Organization's definition of Health: "health is a state of complete physical and social well-being and not merely the absence of disease or infirmity; and good health is held to be fundamental to world peace and security"(B.C.A.S.W 1992,p.2). Social Work practitioners in long-term care facilities are concerned with the social, physical and psychological well-being of the resident, and this includes concern for the family. This is the case for my social work practice. For the past fifteen years, I have practiced social work at the Saanich Peninsula Hospital, a small community hospital that consists of both acute care and long term care beds. It is this experience of working with families, particularly older female caregivers that my curiosity arose. In particular, I am interested in the experiences of older women who continue to be involved in aspects of providing care to their spouses after their admission to long term care.

My clinical work in both the acute and long term care sections of the hospital has provided me a wealth of experience and knowledge of the issues facing caregivers and families. While I am a generalist practitioner, working with people of all ages, the majority of my caseload involves working with individuals who are considered aged. I am well versed in the available community resources and the issues facing elderly patients and "informal" caregivers in caring for a spouse at home, as well as the issues they face in facility placement.

The transition into care has effects not only for the individual coming into care but for the family and the spousal caregiver in particular. The smoother the transition and

the better the ability of the caregiver to link with facility staff and feel supported, the more positive the effect on the caregiver (Whitlatch, Schur, Noelker, Ejaz, and Looman, 2001, p.462). The provision of appropriate, comprehensive care to residents includes support to the caregivers of these residents and an understanding of their concerns and continuing role. Understanding the meanings of their experience is an important step in being able to support the family caregivers. Therefore, I have engaged in a qualitative study that I believe will provide insight into the role of older women who continue to provide care to their spouses.

Context/Background:

Over the last fifteen years I have seen downsizing, restructuring, and regionalization of the health care system. In 1991, the Seaton Report, also known as The British Columbia Royal Commission on Health Care and Costs, presented its report that was titled "Closer to Home". The Seaton Report was a response to the then decreasing federal funding through transfer payments and the fear of the economic downturn (1991).

The report states:

...the principal task facing all British Columbians is to make more effective use of the resources now dedicated to health care. As part of the process, it is necessary to consider ways of shifting resources to the activities and programs, which have been identified as being of the highest priority, and limiting the growth of, or the shrinking of those of lesser priority. At the same time it will be necessary to contain the overall growth of the health care system (p.2).

The results of the shifting focus from acute care services to community services and then the subsequent cuts in community services following the Seaton Report (1991) have affected the delivery of health care and the informal caregivers, primarily women,

who provide the majority of the care for the aged. For social work one of the struggles in acute care has been assisting caregivers in accessing scarcer and scarcer resources.

The community service cuts have increased the burden on families and particularly women who provide care for their dependent loved ones at home. In my experience, I see older and older women well after retirement age spending more and more time doing care tasks. Care service provision is often predicated on whether or not there is a family member who can provide the care. Social views on who provides care are often reflected in legislation that determines eligibility for services (Ketchner, 1999). These views can lead to the expectation that family members will care for their loved ones, and that, community support is provided based on the inability of family members to provide care.

According to Hooyman (1998), in the U.S. system of private health care, “the current public policy option of transferring caregiving work from the public to the private sphere is apparently based on the erroneous assumption that informal structures for providing care (e.g. the family) are under-utilized and simply need to be activated” (p.221). The notion that families do not care for their elderly ‘like they used to’ is in fact a myth (Meddaugh, O’Bryant & Straw, 1991, p.45). In the past, family members did not live as long, and most women, did not work outside the home. “The previously rare experience of having a very old family member is becoming increasingly a typical life event for families, one which could have a dramatic impact on society, at the micro level on families and on the macro level in the health care, pension, and formal support systems” (Kaden & McDaniel, 1990, p.4). Paoletti (1999) states:

It is widespread opinion that now a days older people are abandoned by their families; this is often reported in the media. In fact, though the

opposite is true. Studies show that the families offer a great amount of support to their older members, considering the changes in the composition of the population with an increased number of older people and a decrease in childbirth. There are fewer children to support their older relatives (p.5).

Hooyman (1989) supports Paoletti's statement when she says: "Contrary to stereotypes, the increases in the nursing home population within the past two decades does not reflect familial disregard for elders, but rather the growing numbers of elderly and improved survival rates among victims of chronically incapacitating illness" (p.222). Studies show that family caregivers are providing care for their elderly members (Bould, Sanborn & Reif, 1989; Meddaugh, O'Bryant & Straw, 1991; Walter, 1991; Berg-Weger, Rubio & Tebb, 2000). According to Chappell & Havens (1985), there is support for "...the claims that informal care to aging members is alive and well...this is even true when the elderly individuals are recipients of formal care" (p.227).

In a recent Canadian study, Fast, Keating, Otfinowski and Derksen (2004) found that "there is little public policy in Canada that directly supports caregivers. Exceptions include the federal caregiver tax credit and legislation in a small number of provinces that protects the jobs of employed caregivers (family members) who take a few days away from work to provide care"(p.17). Witt (1994) believes the public ideology in the United States "dictates that families take responsibility for the care of their frail and vulnerable members" (p.65). In Canada, Rice and Prince (2000) find that social policies include the widespread "belief that families (that is women) are the fitting venue for the care of children, elderly relatives, and other dependent members" (p.185). Caregivers who provide care for persons with dementia carry a significant burden in our society (Walker, 1995). There are concerns that current policy developments will only increase this burden

in the coming years.” It would seem that regardless of whether we are looking at U.S. policy or Canadian policy there is an expectation that care is best provided by families.

More specifically as Hooyman and Gonyea (1993) point out:

...hidden in most of these discussions by the very use of the word “family” is the fact that women disproportionately bear the negative repercussions of this shift in America’s social contract to an ethos of self-reliance since caregiving remains predominantly women’s work. Although families provide 70 to 80% of the in home care to older people with chronic illness, it is clearly women-mothers, daughters, daughters in-law, wives, and granddaughters-who provide the majority of this support (p.65).

Social policy appears to be looking at ways of maintaining women as caregivers, not at ways of reducing this societally sanctioned women’s role. Cuts in services and savings in the health care system are, in part, possible because of the increased care provided by women. In my practice I have worked with many family caregivers. However, it is overwhelmingly a gender-specific role as most caregivers are women. In my experience, I have also begun to see a trend of older and older women caring for the elderly.

Older Women Caring for the Old-Old:

Women who are supposedly in their retirement years often are the primary caregivers of their older loved ones. It is not unusual for me to work with caregivers in their late sixties and early seventies. On one occasion, I was called to emergency as an eighty- year old woman had fractured her hip. The issue was not so much that she had fractured her hip, but rather, the paramedics had also brought in her one hundred and six-year-old mother.

Women live longer than men. According to a 2004 Statistics Canada website, “Based on 2002 mortality rates, Canadian men at age 65 could expect to live on average an additional 17.2 years. On the other hand, their female counterparts could expect to live an additional 20.6 on average.” The consequences of this longevity are particular for women. Not only are women the ones living longer, but also it is the “young-old” who are becoming the primary caregivers. According to Alford-Cooper (1993):

Studies demonstrate that most caregiving is done informally by family members, usually the women in the family. About 72% of caregivers are women. Clearly $\frac{3}{4}$ of all caregivers are spouses or children of the care recipient. Approximately one third of caregivers are over 65, and the average age of caregivers is 57 (p.54).

Older adults, both males and females engage in caregiving activities. It is important to note that when we look at the literature on older male caregivers the older men, more than younger men, are providing care for older persons (Pickard, Shaw and Glendinning, 2000, p.726). Bookwala & Schulz found that 25% of the caregiver cohort is male and an older spouse is most likely to be the caregiver for an impaired, community-dwelling older adult (2000, p.603). Given, that women live longer despite chronic illness and will likely out-live their spouses, older women, middle- aged and young-old women provide an inordinate amount of caregiving.

Statement of the Problem:

Given that caregiving can be stressful and burdensome I am curious as to why women continue to engage in caregiving activities after placement. What is the experience of the women who provide such care as feeding, bathing/grooming assistance and dressing? How do women see their role in caring for their institutionalized spouse?

What are their fears and concerns? Is the inculcation of the caregiver role such that, relinquishing these duties is foreign and unthinkable? Are there fears that institutions will not be able to provide the unique and relational care that a home setting can provide? What other caregiving activities are these women engaging in that they see as important?

The time comes when it is clear that women can no longer manage the care of their loved ones even when community services are made available. Accessing long term care beds can be an arduous task as there are long waits for access to beds. Often older women are left struggling at home to manage care until a bed becomes available. There are times when individuals are in acute care waiting for a long term care bed, as it is clearly impossible to manage their care needs at home. It is in this situation that I have garnered my experience in working with older women who are requesting and needing institutional care for their spouses. Saanich Peninsula Hospital, with its attached extended care facility has afforded me an opportunity to see what becomes of individuals once placed in care and how their caregivers are managing; it is here that my research focus arises.

I see women continuing to provide care for their spouses after they are placed in an institution. These women, as I have stated, are often women whom I have watched struggle to provide care at home, and who have become increasingly “burned out,” desperate to get their spouses into care. Facility placement does not end the caregiving relationship for family members but starts a different kind of caregiving relationship, one that is potentially stressful (Kellett, 1999).

This subject is important for several reasons. First, it allows us to get a sense of what older women experience as caregivers of institutionalized spouses, thus adding to

social work knowledge. Second, the experiences of the participants can provide insight into the concerns that participants have with regard to facility placement and can aid in helping residents and their spouses with the transition into placement. Third, professional understanding of older spousal caregivers could lead to better procedures and policies that would reflect, and perhaps coordinate with the participation and contribution that these women make to the care of their spouses.

Assumptions:

This study is based on four assumptions:

1. Social policies like “Closer to Home” mean more responsibility will fall to women. This assumption comes from my experience in the work place, as well as the literature on caregiving.
2. Women continue to provide care in the facility because they do not think that the facility is able to provide the kind of care they would at home. This assumption derives from my experience at work and personal experience with a chronically ill mother.
3. The institution depends on these women to provide needed care activities such as help with feeding. This assumption is from my work experience.
4. Families provide care out of family responsibility. This notion is from my own experience.

Methodology:

I chose an interpretative design, as this is a paradigm I felt would help me in the pursuit of my focus. I was interested in the lived experience of older women. It is the voices of these women that I wanted to hear. It is their stories I am interested in. Reitsma-Street (class handout, 2001), describes the purpose of interpretative designs, as a means “to understand and describe how people experience, create and share meaningful social action.” Developing an understanding of social life, and how people construct meaning in

their natural settings, is the goal of interpretative designs (Neuman, 1997). It is stated in Holstein and Grubriun (1998) “that the social sciences should focus on the ways that the life world, that is, the experiential world every person takes for granted --is produced and experienced by its members” and that “the safeguarding of the subjective point of view is the only but sufficient guarantee that the world of social reality will not be replaced by a fictional non-existing world constructed by the scientific observer” (p.138). Interpretative designs allow for the researcher to be present in the research. Research is not value-free (M. Campbell, SPP 502 class discussion, February 18, 2001). Given my own experience in working with female caregivers, I have opinions and ideas about their experience, and as Dyck says, “Any notion of a simple relationship between the researcher, as the extractor of data, and the researched, as provider of information, has been eroded” (1998, p.9).

Cresswell (1998) outlines five qualitative traditions of inquiry that have a different focus or primary objective. The traditions are as follows:

- 1) Biography explores the life of an individual and provides a detailed picture of their life. Interviews, as well as documents are used. The analysis involves stories, epiphanies and historical content.
- 2) Ethnography describes and interprets a culture and social group. Spending time in the field and documenting observations is the primary data collection method.
- 3) Grounded theory develops theory based on data from the field. Several interviews are required in order to saturate the categories and detail a theory.
- 4) Case Study is a study providing an in-depth analysis of a “case” or “case study.” Documents, archival records, as well as, interviews and observations are utilized.
- 5) Phenomenology focuses on the essence of experience about a phenomenon. Data gathering involves extensive unstructured interviewing. Statements and

themes are extracted and a detailed description of the meaning of the experience is provided.

My line of inquiry involves finding meaning; therefore, phenomenology is suited to answer the question. The goal of a phenomenological approach is to gain a rich, thick description of a given phenomenon, in this case the lived experiences of older women providing care for their spouses in a long term care facility.

Summary:

My curiosity about the experiences of older women providing care to their spouses in long term care arose out of my experience working with the elderly in both the acute care and long term care setting. Policy changes involving the provision of care services have affected the family caregivers, especially women. The following chapters include a review of the literature, a discussion of the research design, a discussion of the findings, and lastly the final chapter presents a conclusion and a summary.

CHAPTER TWO: LITERATURE REVIEW

In reviewing the literature, I was looking for research that pertained to older women as caregivers. In particular, I was interested in research that looked at caregiving post placement. The literature that I reviewed was predominately concerned with family caregiving, although the majority of the subjects of study were female. The following literature review addresses women as caregivers in the broader context. From the literature six points emerged with regard to women and caregiving both pre and post facility placement.

- 1) Women as caregivers is a socially constructed role
- 2) There are personal consequences, such as, depression, anger, anxiety, frustration, loss of self and emotional exhaustion for women who have caregiving responsibilities.
- 3) There are financial consequences for these women, due to intermittent activity in the labour market and in some cases the requirement of early retirement
- 4) The nature of the relationship between caregiver and care receiver is important.
- 5) The role and nature of the relationship between staff and family caregivers can affect family caregivers negatively.
- 6) The nature of the visiting role of family caregivers.

Caregiving as Predominately Women's Work:

Despite the increased aging of the population, and despite smaller families, as well as the increased role women play in the work force, women provide the majority of the caregiving required by elderly persons. Caregiving historically has been seen as women's work. Some of the research focuses on caregiving as a 'women's issue'

focusing on the who of caregiving (Alford-Cooper, 1993; Hooyman and Gonyea, 1993; Kaden and McDaniel, 1990; Matysiak, 1998; Paoletti, 1999; Pohl, 1998; Rice and Prince, 2000; Richardson, 1999; Walter, 1991; and Witt, 1994). This research indicates clearly that women are the predominate providers of care.

What is it that renders women the societal caregivers? Some of the literature focuses on the reason for women being the primary caregivers in society. This, of course, in part is the age-old argument of nurture vs. nature. Is it that which makes us mothers that leave us to be caregivers evermore? Do we have an innate tendency to care more than men do, or is this only a socially generated role? Witt (1994) looked at the question of whether biology or socialization to gender roles was more closely associated with women's majority role in filial caregiving. Her research, which includes a historical perspective, indicates, "socialization to gender roles is more closely associated than biological 'nurturing' behaviour with the greater tendency for women relative to men, to perform caregiving tasks" (p.66). Hooyman and Gonyea (1993) believe that the crucial role gender plays in the hierarchy of obligation to provide care, moves from spouse to daughters to daughters' in-laws, not to sons and brothers, therefore reflecting a pattern of societal expectations that caregiving is a female characteristic (p.150). Both Hooyman (1989) in the U.S.A. and Paoletti (1999) in Italy, find that women experience careers of presumably natural stages of caregiving beginning with children and moving on to older relatives and grandchildren (sometimes simultaneously), then to elderly spouses.

Studies of older couples remain under-researched according to Davidson, Arber and Ginn (2002) and the care given by older men to their ailing wives has been largely neglected. The research on male caregivers may be neglected but is not totally ignored.

Kramer (2000) focused her research on male caregivers, and many other research studies, for example Zarit and Whitlatch (1992), focus on families including males. Millar (1991) found in her study that husbands more frequently performed lifting and mobility assistance at lower levels of physical dependency while wives were more likely to perform personal care tasks at high level of need and impaired wives more frequently assisted with household chores. Millar suggests this finding provides evidence for elements of both the gender role and social role hypothesis.

Cancian and Oliker (1999) take the gender argument a step further and assert that because caregiving is viewed as instinctively a female ability, the knowledge and skills required are unrecognized, and therefore paid caregivers i.e. professional caregivers, are underpaid. Further, the authors believe that the gendered organization of care not only “subordinates women, it also subordinates and devalues caring” (p.151).

Consequences of caregiving:

The literature also looks at the consequences for women as they take and maintain the role of informal caregiver. In Paoletti’s study (1999) of female Italian caregivers, she found that:

In the case of relatives cohabiting with the disabled older person, caring means staying at home, being confined to the home all the time. This is a source of intense stress and health problems for some caregivers. The most noticeable consequences on the care’s health were in relation to construction of the caring as an inescapable destiny...” (p. 65).

Physical exhaustion, and emotional stress experienced by caregivers can have serious negative effects (Zarit, 1998; Zarit & Whitlatch, 1992; & Richardson 1999). The effects include symptoms such as depression, anger, anxiety, frustration, guilt,

sleeplessness, demoralization, feelings of helplessness, irritability, lowered morale, and emotional exhaustion (Richardson, 1999). Bookwala and Schulz (2000) found that, "...female caregivers report experiencing a greater 'loss of self'...a loss of self, that is, a loss of who one is, and a loss of an important part of oneself as a result of taking on the caregiving role was associated with greater restrictions on social contacts and fewer social roles outside of the caregiving role" (p.613).

Financial Consequences of Providing Care

Not only are there health consequences for women who take on the caregiver role but there seem to be financial consequences. Women often enter and leave the work force based on childrearing needs. Limitations in maternity benefits have left many gaps in women's economic security. Women often leave the workforce for years at a time, thereby forfeiting seniority benefits and pension vesting years. According to the literature on women and caregiving, women also leave the workforce and/or change their employment status from full-time to part-time, because of the care needs of elderly family members (Richardson, 1999).

The Older Women's League Report describes the impact of caregiving on women caregivers: "...they note that women often take less demanding jobs because of the physical and emotional energy required to care for children and aging parents, or they take time off from paid work to do caretaking work" (Witt, 1994, p.69). Pohl, Collins and Given (1998) state, in their study that one of their participants, "a daughter caring for her mother took a major and permanent demotion from a key administrative position to a less pressured one in order to provide care" (p.66). Another participant, "a married daughter

who was employed quit her job to provide care and found that difficult; 'I loved it, I loved it', referring to her job" (p.68). Women also make retirement choices based on the needs of loved ones. " Several researchers have documented that when it comes to decisions about retirement women consider their family situations more often than men do" (Richardson,1999, p.58). Part-time employment, under-employment and early retirement can affect a woman's financial situation negatively. " These women's decisions not to work or to give up work to care for an elderly relative may exacerbate women's economic dependency in old age" (Kaden and McDaniel, 1990; p.22). Many retired women, in contrast to retired men, face poverty in retirement. The reason for this poverty is multi factorial; life long gender inequality, life long involvement in caregiving; and inequalities in retirement policies (Richardson, 1999).

Caregiving is a women's issue and several feminist researchers have looked at the consequences, including the economic, physical and emotional results (Hooyman, 1998; Witt, 1994; Hooyman and Gonyea, 1993; Matysiak, 1999; and Richardson, 1999). Witt (1994) states: "Public policies, work place structures, and socialization to familial obligation assure that this gendered division of labour will continue unless challenged, debated, and redirected in the public and political arena" (p.66).

The Nature of the Relationship

It appears from the literature that caregiver well-being is also determined by the relationship between the caregiver and the care receiver. In a study of mother-daughter relationships, with the daughter as caregiver, the daughter's well-being was determined more by the previous relationship she had with her mother. In addition, cohabiting with

the care recipient appears to increase the incidence of a negative impact such as increased depression (Berg-Weger, Rubio, & Tebb, 2000; Paoletti, 2000; Blieszner, Usita & Mancini, 1996; Conway-Turner & Karasik, 1993; Walter, 1991). Further, there is evidence to show that the emotional support required and the effects of a changing relationship such as parenting a parent have negative effects on caregiving (Walter, 1991; Kane, Reinardy, Penrod, and Huck, 1999).

Ross, Rosenthal & Dawson's (1993) review of the literature on caregiving found that "in addition to being physically at risk, spouses are at greater risk for emotional distress than other caregivers" (p.1532). The most common problem for elderly wives is the loss of the relationship, missing the way their spouse was prior to the onset of illness (Ross et al.1993, p.1532.) Moreover, Ross et al. (1993) reported caregiving wives experienced similar degrees of burden to that experienced by caregiving husbands but that wives reported more depression and greater deterioration of the marital relationship.

Some feminist researchers, specifically Matysiak (1998), warn that feminist researchers need to be careful in outlining the oppressive nature of caregiving, as many of the "issues involved in care seem to be viewed as dichotomous, without recognition of the myriad factors that mediate all caring situations...simplistically put caregivers are seen as one group, while people who require support are seen as another mutually exclusive group" (p.26). The point being made is that some examinations discount or do not recognize the nature and relationship of familial caregiving. Connidis (1989) suggests that interdependence develops in older marriages because caring for a spouse increases isolation and a feeling of being cut off from the rest of the world.

Providing Care in an Institutional Setting:

Research related to caregivers and institutional care, is limited and focused on the depression and stress levels of caregivers after placement of loved ones (Zarit, 1998; Zarit and Whitlatch, 1992). Kellett (1999) finds that, “there is a tendency in this research culture to focus upon family carers only when they are stressed and not functioning well” (p.1474).

Research suggests that caregivers do not abandon their loved ones once placed in a facility (Pratt, Schall, Wright, and Hare, 1987). Admission to facility care does not signal the end of caregiving for caregivers, but rather, signals the beginning of a different but still potentially stressful involvement (Kellett, 1999). In their study of the transition to facility care Zarit and Whitlatch (1992) found, that relatives visited often and helped with feeding and personal care. “The careers of caregivers do not stop at the institution’s door but continue in an unaltered and still stressful way...caregivers do not give up their role; they shift their responsibilities” (Zarit and Whitlatch, 1992,p.672). Ross et al. (1993) note that “families continue to participate in care in a variety of ways...they monitor patients and notify nurses when something untoward happens, they carry out tasks such as providing comfort measures, even going so far in some cases as carrying out most of the nursing care required, and they participate in decisions regarding treatment”(1535).

Relationships between staff and family caregivers:

Ross, Rosenthal and Dawson (1993) state, “Despite feelings of relief that relatives and/or husbands are receiving the care they need and can no longer receive at home, admission into a long-term care institution signals a period of adjustment for families that is frequently fraught with emotional struggles” (p.1536). There is discussion in the

literature that relationships between staff and family caregivers can be a source of stress for caregivers. Clarification of roles and tasks, as well as integrating into the institutional milieu, can present problems for the family caregivers. Several researchers have looked at the relationships between family caregivers and staff, and found that successful partnerships are dependent on the degree to which both families and staff accept and understand their roles and responsibilities vis-à-vis each other (Ross et al. 1993). Caregiving in the home has an autonomy that is relinquished at the door of the institution. Care tasks in the home are carried out and determined by the needs of the care receiver and care provider. Friedemann, Montgomery, Rice and Farrell (1999) report, that most of their research subjects found institutionalization of a loved one incongruent with their usual patterns. Once in the institution care is determined not by individual need alone but by the needs of several individuals, staff availability and administrative priorities.

Staff often view family members as problematic, especially when family members are critical of the performance of the staff. It has been my experience, that I get many referrals to see family members because staff believes them to be complaining or difficult. Families take stock of the facility environment, inspecting it for what seems right or does not seem right, according to their sense of order; intruding in the activities that otherwise, have a social logic of their own (Ross et al., 1999). Ejaz, Noelker, Schur, Whitlatch & Looman (2002) found in their study that "family members who perceived that significant improvements were needed in direct care had more negative interactions with other staff and gave more help with activities of daily living (ADL) to their relative" (p.379). Institutionalization is not just the turning over of care from family member to

institutional care workers, but also a relinquishing of care and control that was the prior experience.

Family Caregivers as Visitors:

Several of the articles referred to family caregivers as visitors and looked at the role of visiting. Buckwalter and Hall (1987) argue that residents in facilities are often considered by the staff as “theirs” and that the family members are relegated to the status of visitor. Families are often, according to Buckwalter and Hall (1987), “assigned to bring hearing aid batteries and toiletries, and so on, and, perhaps criticized if visits are too frequent, too long, or otherwise conflict with nursing home routines” (p.178).

In looking at the experiences of older wives of institutionalized spouses, Ross, Rosenthal and Dawson (1993) also refer to these women as visitors. According to them, “visiting becomes an aspect of their lives that is fraught with resignation, frustration and contradiction” (1534). Ejaz, Noelker, Schur, Whitlatch and Looman (2002) found that family relatives of institutionalized elderly often go through a stressful transition from the primary caregiver to visitor.

Ross, Rosenthal and Dawson (1993) found that the patterns of visiting for elderly wives were “characterized by a high level of frequency that continued overtime” (1534). Yamamoto-Mitre, Anestensil, & Levy-Storms (2002) looked at the patterns of visiting for family members and state:

In general spouses visit more often and spend more time visiting than adult children...visiting daily is higher for spouses than visiting weekly. Married persons share a unique relationship that may account for the intense involvement with husbands and wives. In addition, these married persons are mostly older themselves and therefore, may have greater

latitude in devoting large amounts of time to caregiving than in the case of adult children (p.S245).

In an Australian study looking at the meaning of visiting a spouse in residential care, Tilse (1997) found that the purpose and meaning of visiting included “maintaining continuity of self, the pattern of daily life, demonstrating commitment, expressing attachment, coping with grief and loss and avoiding loneliness” (p.201).

Summary:

My research interest in the lived experiences of older women who continue to provide care for their spouses in facility care arose from my experience working with caregivers, primarily female caregivers. The focus of social policy, emphasizing care at home, has burdened women. The research finds women to be the primary caregivers with care responsibilities passing from mothers to daughters and that caregivers do not abandon their loved ones once placed in care facilities. There are consequences to providing care to family members and yet, given these consequences experienced by caregivers, they continue to provide care to their spouses after facility placement.

While the literature speaks to levels of depression in caregivers after institutional placement of their loved ones, it does not answer my particular lines of inquiry. What is it that keeps these women, daily in some instances, providing ongoing care and assistance with activities of daily living (ADL's) well after their loved one is admitted to a facility? What I am curious about, given the consequences outlined by various researchers, is why women continue to provide care once their loved one has entered a care facility. It is the voices of these women that I am interested in and, therefore, in order to explore the lived

experiences of women over seventy who provide care for their institutionalized spouses, I
engaged in an interpretative study.

CHAPTER THREE: RESEARCH DESIGN

This research addresses the experience of older women providing care to a spouse after facility placement. The purpose of the study was to provide an in-depth exploration and description of the lived experiences of older women who continue to provide care to their spouses in a long term care facility.

I engaged in an interpretative study and the following chapter outlines and discusses the methods and procedures chosen. The methodological description includes a discussion on the underpinnings of phenomenology, data collection, data analysis, ethics and rigour.

Phenomenological Framework:

The goal of a phenomenological study is to gain a rich description of a phenomenon. In this study the phenomenon is the experiences of older women providing care to their institutionalized spouses. I have used the work of John Creswell as a guide to conducting this research. Phenomenology is the approach, according to Creswell (1998) that is appropriate for studying individuals in order to learn about their experiences. The result of this endeavour is a description of the essences of these experiences.

Heidegger, a German philosopher who was a scholar of phenomenology, believed that humans make meaning out of their everyday experience, both in conscious and unconscious ways. Experiences are contextual and different experiences, values and beliefs will create different meanings for different individuals. However, shared meanings are possible when individuals inhabit worlds that have similarities such as

language and culture. Creswell (1998) says that a set of philosophical assumptions about knowledge guide a qualitative study and they are:

1. Knowledge is within the meanings people make of it.
2. Knowledge is gained through people talking about their meanings.
3. Knowledge is laced with personal biases and values; knowledge is written in a personal, up-close way.
4. Knowledge evolves, emerges, and is inextricably tied to the context in which it is studied.

The participants I interviewed bring to their experience common sense constructs and categories that are social in origin. The participants have ideas and notions about what makes their experience meaningful. I believe that there are common experiences and meaning-making by the participants that will increase our knowledge and understanding of their experience.

Phenomenological research involves researchers looking for the essence, the underlying meaning of the experience under study, and emphasizing the intentionality of consciousness (Cresswell, 1998). Therefore, by engaging in this research design, I could bring the voices of the women to the forefront and expose the meaning of providing care for their spouses after facility placement.

As stated earlier, the researcher in a qualitative study is not an objective observer uncovering objective data for analysis, but rather an active participant that influences and affects the research. I recognize that as a social worker having experience working with women who are in the same situation as the participants, I have assumptions and opinions about the phenomenon. I also recognize that I cannot completely put these aside. I do hope, however, that by reflecting on and identifying my thoughts and feelings and setting

them aside, I will be able to understand the experiences of the participants as they report it. According to Creswell (1998) “the concept of epoche is central, where the researcher brackets his or her own preconceived ideas about the phenomenon to understand it through the voices of the informants” (p.54).

Creswell (1998) outlines five reasons for conducting qualitative research:

1. When you want to describe what is going on, and the research question starts with a how or what.
2. When the topic needs to be explored.
3. When there is a need to provide a detailed view of the topic.
4. When you want to study individuals in their natural setting.
5. When the researcher has an interest in writing in a literary style and can bring herself into the study.

I believe that this study meets the criteria for conducting a qualitative research study and that the tradition of phenomenology is best suited for addressing my research interest.

Data Collection and Analytical Procedures:

Phenomenological research employs the extensive interview as the method of gathering data. I interviewed four participants from a local facility, not one to which I am connected. In qualitative research, a representative sample is not the same as in quantitative research. In a qualitative research design, any subject belonging to the group under study is eligible (Sandelowski, 1986). The participants in my study were eligible because they were: women over seventy; women who have spouses in facility care; women who are providing care to those spouses such as bathing, feeding and dressing; and women who are willing to participate in the research.

I produced an information poster citing the purpose of the research and invited the women who met the criteria, and who would be willing to participate to call me. Initially, my plan was to post the poster in the facility where women would see it. The facility did not want me to put the posters up, so they were photocopied and given to the program management staff to pass out to anyone they identified as appropriate participants in the study. Having the program management team choose which women might be potential participants could suggest selection bias was introduced into the research design. This posed a dilemma, as the research was not open to all possible participants. It is possible that other criteria may or may not have been introduced by the pre-screening activity of program management staff. However, upon reflection, I believe that the potential for selection bias was minimal. Program management staff merely chose those women who would be willing and able to participate in the study since they were experiencing the phenomena I was interested in exploring.

While the program management staff did advise the women of the study and provide them with my contact information, the women themselves volunteered for the study by calling me directly. In order to keep the identity of the women who chose to participate confidential, I did not advise the program management staff who contacted me.

Five women called me. One woman called me because she recognized my name: she had been a neighbour of my parents when I was born and felt an obligation to help me out, although she really did not want to participate. Two issues arose: 1) She did not want to participate; and 2) her previous relationship although, I did not know her directly, could have been seen as a conflict of interest. Therefore, I excluded her from the study

and interviewed four participants. Conducting the interviews was the most enjoyable part of the research process. Working with people and speaking to them about subjects that are personal and that sometimes involve emotional circumstances is not unfamiliar. The participants willingly and openly provided me with an insight into their lived experiences.

The Participants:

I have used pseudonyms in order to protect the identity of the participants in the biographical sketches of the study participants. The sketches are provided in this thesis to introduce the participants of the study.

Kathleen

Kathleen is 78 years old and her husband has been in care since 2000. He suffered a stroke and spent several months in a transitional care unit. Kathleen brought him home and cared for him until he was placed in the facility. She had very little home help, as she found it more problematic with the constant turnover of staff and the limited tasks that the homecare could perform. Once a bed was offered she was reluctant to have him go, but her family persuaded her to place her husband in care. Kathleen goes to the facility daily, sometimes twice a day. She is very involved in her spouse's care including physical and emotional care.

Mary

Mary is 79 and her spouse has been in care since 2000. He had been in declining health from Alzheimer's type dementia, but she managed him at home for several years. Mary did not have home support but did utilize community services such as daycare and

the community-bathing program. After an acute episode involving hospitalization, Mary's family and doctor suggested her husband be placed in a facility. She was not able to access the facility of choice, so her husband spent several months in another care facility until he was moved to his present location.

Mary is very active in her husband's care and attends the facility six days a week, sometimes twice in a day if a special event is happening. Mary has hired someone to be with her spouse on the one day a week she does not go to the facility. Her caregiving activities involve social and emotional care activities. She is also very active in fundraising for the facility.

Shawna

Shawna is 87 and her spouse has been in the present facility since 2001. Prior to his admission in the present facility, he was in an intermediate care home for a year. Shawna noticed her husband's decline in health and had to convince both her family and the family physician that her spouse was having difficulties. He has dementia, and she cared for him at home for several years until her health prevented her from continuing. Shawna is residing in a supportive living home but still goes to the facility to see her husband three times a week. She is involved in her husband's social and emotional care and participates in activities that keep him active and as alert as possible.

Pamela

Pamela is the youngest participant at 71. Her husband has been in care the longest since 1999. He had to retire early due to Parkinson's disease. For several years Pamela cared for him at home, and they had devised a routine that worked well for them. Due to the immobility experienced by her husband in the mornings, the a.m. routine was very

specific and involved Pamela being very active in his care. After a particularly bad fall, her husband was admitted to hospital. While there, it was the health care team who decided that her husband required placement. Her husband went to another facility while waiting for the facility in which he is presently residing.

Pamela is very involved with her spouse's care in the facility and goes daily. She not only attends to the emotional and social care needs of her spouse but also his physical needs as well. She does a lot of his care that involves grooming and also does physical exercises with him.

Conducting the Interviews:

I decided beforehand that the interviews would not take place at the facility, as this would jeopardize confidentiality. I left it up to the participants to choose the place in which the interviews would take place. All of the interviews took place in the participants' home. The participants all made me very welcome in their homes, and their willingness to help a student was not in any doubt as they all fed me in delicious and great quantities. The participants were very willing and eager to share their experiences of having a spouse in facility care. All the participants lived independently. One participant lived in a supportive living home also known as congregate housing, whereby meals are provided in a common dining room.

The semi-structured interviews were audio taped. The semi-structured interview allows for flexibility and the capturing of insights that may have otherwise been lost (Connell, Lynch and Waring, 2001). The interviews were conducted in such a way as to invite each participant to tell her story. I made a list of questions rather like a "cheat sheet" that I used as a guide (see appendix # 1). My own experience as a social worker

who engages people in interviews and counselling helped me with the interview process. In my practice, interviews with clients are neither structured nor purposeless. Interviewing clients is not unlike a social conversation that has a goal and purpose. While the direction of the conversation can change, and one cannot predict what will be disclosed, there are questions, that while not being directive or structured, can get the conversation back on track in order to achieve the goal. As Kvale says:

The structure of the research interview comes close to an everyday conversation, but as a professional interview it involves a specific approach and technique of questioning. Technically, the qualitative research interview is semi-structured: it is neither an open conversation nor a highly structured questionnaire (1996, p.26).

During the interviews, I utilized the nine types of interview questions that are outlined by Kvale (1996, p.131):

- | | |
|---------------------------|----------------------------|
| 1. Introducing Questions | Can you tell me about |
| 2. Follow-up Questions | Nods or “mm” encouraging |
| 3. Probing Questions | Can you say something more |
| 4. Specifying Questions | What did you do |
| 5. Direct Questions | Did you |
| 6. Indirect Questions | Have you ever thought |
| 7. Structuring Questions | But I am wondering about |
| 8. Silence | Not filling in pauses |
| 9. Interpreting questions | Rephrasing answers |

Primary Research Questions:

The primary research questions as outline in Chapter One were:

1. What is the experience of the women who provide care such as feeding, bathing/grooming and assistance with dressing?
2. How do women see their role in caring for their institutionalized spouses?
3. What are their fears and concerns?
4. Is their caregiver role such that relinquishing these duties is foreign and unthinkable?
5. Are there fears that the institutions will not be able to provide the individual care that the home setting could provide?
6. What other activities are these women engaging in that they see as important?

The interviews were scheduled for 1 to 1.5 hrs. I spent two hours with three interviewees and over two hours with one. Kvale (1996) describes the research interview as a type of conversation that seeks to obtain knowledge through the subject's world. The participants were generous with sharing their experiences and sometimes would take me down tangents of conversation that, while not directly speaking to the experience of caregiving in a facility, did provide richness to my understanding of their experience. At one point during one of the interviews, I moved out of the student researcher role into my role as social worker. The participant spoke about a situation that she presently was experiencing and she had some erroneous information. I felt it necessary to provide her with the correct information just as I would had I been her social worker in the facility.

I planned on meeting with participants twice, but for practical reasons and due to my timelines, I decided to forego the second meeting. The second meeting would have

been a member check. Member checks are sometimes done in qualitative research as a way of increasing the rigor of the work, and as a way of establishing the validity of the interpretations of the data collected (Sandelowski, 1993). Member checks are discussed further in the rigor section of this chapter.

I did do a follow-up phone call to all the participants as I had outlined in my ethics submission. Anytime participants are interviewed about their experiences there is potential for feelings and emotions to be realized that may create problems or concerns for participants. My follow-up calls were to see how the women were doing and see if they were having any repercussions from the interview. None of the participants reported any concerns. The follow-up call also turned out to be an opportunity for the women to tell me about their experience of being interviewed. Information from this conversation was not considered data as the follow-up calls reflected the experience of being interviewed, not of the phenomenon being explored in this study.

Additional Methodology: The use of a Reflective Journal:

As I prepared for and conducted the analysis, I kept a journal, a notebook for self-reflection. This helped to make visible my existing assumptions and how these assumptions energized, puzzled or influenced my understanding of the data. The journal also enabled me to note the emotions and intonations that added richness to the answers provided by the participants. The notebook was divided into several sections. Each participant had a section that I would write my thoughts in after each interview session. I also used this notebook to jot down the many musings and thoughts about the study that would suddenly and invariably come to mind at the oddest of times.

Analyzing the Data:

Analyzing the data started by having the audio-taped interviews transcribed by a professional. Given the time that would have been required to transcribe the interview tapes, I chose to have a professional transcribe them. I read the transcripts while listening to the tapes to ensure the validity of the transcripts.

The data analysis process, while seemingly daunting at times, was also the most creative. The data analysis in phenomenological studies is an inductive process. Rather than themes, and categories being imposed on data prior to collection, inductive analysis involves the emergence of themes and categories from the data (Dye, Schatz, Rosenberg & Coleman, 2000). The interviews produced a large amount of raw data. The process of analyzing the data involved sifting through the data, not unlike making a stew where the bits of data are boiled down until the essence of the experience is made visible.

The data analysis proceeded “through the methodology of reduction, the analysis of specific statements and themes, and a search for all possible meaning “(Creswell, 1998, p.52). Following Creswell’s approach, I extracted statements of significance (described in the following section). I then categorized these statements into meaning statements and categorized them according to topic. At this stage, one of the approaches I used was horizontalization. Horizontalization is a procedure whereby data are transformed into clusters of meanings, or statements of significance, that are tied together to make a general description of the experience (Creswell, 1998). These are also referred to as natural meaning units, or ‘nmu’ (Pietersen, 2002). Themes emerged, and culminated in a description of the meaning of the experience. A description of the experience is presented in Chapter Four.

Statements of Significance:

After reading the transcripts and listening to the four interviews, as discussed earlier, I embarked on a phenomenological analysis. Statements of significance were selected from the transcripts. As this study is about the experiences of the participants it was important to present their voices and therefore, the statements presented are verbatim and include idiosyncratic use of syntax.

The following table of statements of significance is not exhaustive. After the initial reading through of the transcripts, I highlighted statements that I saw as being relevant to the topic, eliminating statements that involved the relationship building between myself and the participants, or those that were not about the experience of providing care to a spouse in a facility. While transcripts were read individually, I also engaged in a constant comparison, going from one transcript to another, as statements were recognized and recurrent. I was able to identify bits of data, which could be related for the purpose of comparison: participant one said this about such and such and participant two said something else, about such and such. At first repetitiveness aided my judgments about when a statement was important or illuminating in terms of the experience. However, not all of the participants experienced the same phenomenon in the same way, and therefore I included those statements that were atypical as well.

I listed sixty-one dominant statements of significance in table 1. Given that this study is not a comparative study, I did not include descriptive statements that involved life before placement excepting those around decision making about placement and those that indicated a change in what they used to do and what they still do. Statements that have relevance to the experience or describe the experience are included.

Table 1: Statements of Significance:

- | | |
|--|------------------------------------|
| 1. He still knows me | 30. Keeping active |
| 2. I will say “do you remember this”
or “do you remember that” | 31. Continue caring |
| 3. I would bring him home cook up oysters | 32. A duty |
| 4. I was really worried | 33. Useful a sense of purpose |
| 5. Well I like to be with him | 34. If I wasn’t going there |
| 6. He looked after me for 50 years
and now I am looking after him | 35. Supposed to have TLC |
| 7. I look forward to spending the afternoons
with him to me it’s relaxing | 36. They appreciate it |
| 8. I like to relax in the evenings because I’m tired | 37. They didn’t let me know |
| 9. Keeping him active | 38. Nobody listens to you |
| 10. He knows I’m there | 39. Happy when I come in |
| 11. My life changed radically | 40. Not enough help |
| 12. I really miss him/I feel alone | 41. Nurses know I do it well |
| 13. Not just doing things for spouse but the lodge | 42. Love to help |
| 14. They didn’t know | 43. I do a lot of things |
| 15. No choice | 44. If it were me |
| 16. Needs me to take over | 45. If I were not there |
| 17. Decision about placement | 46. What I’d need in that position |
| 18. Do his laundry | 47. If I’m there I take him |
| 19. You have to keep on top of things | 48. It’s not easy |
| 21. They never noticed | 49. Yourself means nothing |
| 22. Couldn’t look after him | 50. I want to protect him |
| 23. Keep him interested | 51. Sundays he comes home |
| 24. Very difficult | 52. Crosswords |
| 25. I knew | 53. Keeping him mentally alert |
| 26. Reminisce with him | 54. Trouble feeding himself |
| 27. Exhausted, it’s work | 55. No pay |
| 28. I felt responsible | 56. The sight of me |
| 29. He’d disintegrate | 57. I know what he is saying |
| | 58. I make it easy for him |
| | 59. Make him feel good |
| | 60. Always have something bring |
| | 61. I stand up for his rights |

The statements of significance were further categorized by clumping together those statements that were similar, creating categories. Dye, Schatz, Rosenberg and Coleman (2000) refer to this as the Initial Category Set, whereby statements of significance are placed into “piles according to their look alike, feel alike qualities” (p.3). “The fit between data and categories—the process of developing categories—is one of continuous refinement” (Dye, et al., 2000, p.3). The statements of significance were raw

bits of data already chosen for their illuminating quality. I had to decide what to do with the data and organize them into a form that was manageable.

I moved statements of significance into separate categories. Using my computer, I created eight electronic files to house the categories that I added to and revised as I reviewed the data. Grouping together statements of significance resulted in the following categories: Activity, You Know, What they used to do for their spouses, What they still do for their spouses, Feelings/Emotions, Decision-making, Memory, and Role Tension.

1. Activity included all the statements of significance that involved the activities carried out by the participants with their spouses. Such activities included taking their spouses for walks, taking them to activities, doing crosswords, as well as doing warm up exercises prior to physio therapy.
2. You know was a file that included the statements the women made when describing what they know about their spouse, claiming expert knowledge.
3. What they used to do for their spouse contained those statements that referred to activities including care activities that they did prior to their spouse's admission to a care facility.
4. What they still do for their spouses included statements whereby the women stated they still do such and such.
5. Feelings/Emotions included the statements involving their feelings about their spouse, about placement and about their role.
6. Decision making included statements the participants made about making decisions for their spouse, and decisions that were made by others for their spouse.
7. Memory was a file I created that included those statements made by the participants discussing activities they engaged in with their spouse that involved memory activities.
8. Role tension was created to include statements that indicated tension between the participants and the staff in the facility.

A decision to place particular statements of significance in particular categories was based on external heterogeneity. I looked for similarities within and across each

interview. Several statements of significance could be placed in more than one category. For example, several statements were made by the participants as to activities they did with their spouses, and I created a category to capture these called Activities. Statements were also made by the participants about activities involving memory. I kept these two categories separate because the activities involving memory seemed to be unique, involving a form of reminiscence. The richness in the data warranted inclusion in both categories.

All statements of significance that referred to the above-mentioned categories were placed in one or more of those files. Within these eight files, several common themes emerged. Such common themes were delineated by similarity, a repetitive word or phrase. The thematic analysis and description of the experience of older women providing care for a spouse in a long term care facility will be discussed in the following chapter.

RIGOUR:

Phenomenology is successful when readers understand the meaning of the experience. Validity, generalizability and reliability in the positivist design or, what Kvale (1996) refers to, as the “Holy Trinity” of modern science, are not attempted within the interpretative designs. However, one knows the research is of good quality if the research is plausible, makes sense, contributes to theory building and gives insight into the phenomenon. “There are multiple ways of knowing and multiple truths, and the concept of validity indicates a firm boundary line between truth and non-truth” (Kvale, 1996, p.231). Lincoln and Guba (1985) suggest that a qualitative research study must be trustworthy. Sandelowski (1986) says, “The truth value of a qualitative investigation

generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conception of those experiences. Significantly, truth is subject-oriented rather than researcher-defined.”(p.30). Utilizing the work of Sandelowski (1993 and 1986), Lincoln and Guba (1985) and Hycner (1985) I have outlined four areas, that I believe address the question of rigor in my study; credibility, transferability, dependability and confirmability.

Credibility:

A qualitative study is credible when its descriptions and interpretations of a particular experience would be recognized by those who have had the experience (Guba and Lincoln, 1981). By rereading the transcripts while listening to the audio-tapes, I have validated that the words used and analyzed were indeed those of the participants. The participants would recognize their words. Having the interviews transcribed verbatim enabled me to capture adequately what the participants said and to ensure that I did not miss anything that would add to the analysis. During the interviews, when I made mental interpretations from participants' stories I would check back with them to see if I understood correctly or interpreted what they said accurately.

Quantitative research, with its emphasis on objectivity and internal validity, differs from qualitative research, which acknowledges the relationship between investigator and subject. “Since a major threat to the truth value of a qualitative study lies in the closeness of the investigator-subject relationship, the credibility of qualitative research is enhanced when investigators describe and interpret their own behaviour and experiences as researchers in relation to the behaviour and experiences of subjects”

(Sandelowski, 1986, p.30). I wrote in my journal my experiences and interpretations after each interview.

I believe that the study has credibility because I collected the data in such a way as to enhance the possibility of capturing multiple realities of the experience. The study would have had increased validity and credibility if I had returned to the participants with summaries of the first interview as a way of checking back. Lincoln and Guba (1985) and Sandelowski (1993) refer to this as “member checks”, where the researcher checks back with the source to ensure that her interpretations and the data collected were accurate. However, as Sandelowski (1993) states, “The stories that the members tell in interviews are themselves constantly changing. They represent members’ efforts to order, find meaning in, and even live with the events in their lives to a particular moment in their lives” (p.5). Therefore, while it is arguable that rigour may have been enhanced by conducting member checks, I do believe I captured the meaning of the participants experience as they reported, for that particular point in time.

Transferability:

In a qualitative study, transferability refers to the ability to generalize the findings or render the findings relevant to another similar situation. According to Hycner (1985) “...in the process of even investigating the experience of one individual, we can learn much about the phenomenology of human beings in general. Though the results in the strictest sense may not be generalizable, they can be phenomenologically informative about human beings in general” (p.295). Purposeful sampling was such that the subjects recruited could illuminate the phenomenon being studied. I used the words of the

participants throughout chapters 3 and 4 so the reader would have an understanding of why I made a given interpretation, thus making the study more dependable. I believe that the information and essence of the experience garnered from the analysis of the data gathered from the four participants will add to knowledge. Further, I believe it will provide insight into the experience that others may face when they continue to provide care to their spouses in a facility.

Dependability:

Dependability refers to the notion that the readers of the research would share the same interpretations. Lincoln and Guba (1985) state that “an inquiry must also provide its audience with evidence that if it were replicated with the same or similar respondents in the same context, its findings would be repeated” (p.4). As there can be no validity without reliability, so there can be no credibility without dependability; therefore Lincoln and Guba argue that dependability does not have to be demonstrated (1985, p.4). Nonetheless, my use of direct quotes from the participants demonstrates why I made a given interpretation, thus increasing dependability.

Confirmability:

Confirmability refers to the degree to which the findings are not a priori knowledge of the researcher. Confirmability is assured when an audit trail can be followed ensuring that conclusions, interpretations, and recommendations can be traced to their sources, and that they are supported by the inquiry (Lincoln and Guba, 1985, p.4). Auditability is achieved when other researchers can follow the decision trail used by the

investigator in the study, and can arrive at the same or comparable conclusions (Sandelowski, 1993). I have followed the steps suggested by Sandelowski in achieving auditability (1986):

1. I discussed my interest in the topic
2. I reviewed the literature on women and caregiving
3. I provided the purpose of the study
4. I described the participants and the sample criterion
5. I described how the data was collected
6. I described the analysis

ETHICAL CONSIDERATIONS:

All research through the university must be vetted through the Human Research Ethics Board and I did receive the clearance to conduct my research. The facility involved in my research requested a copy of my 'permission to proceed' as part of their vetting process. Because researchers are often in a position of power and because I believe informants need to feel free to refuse to participate in research, I conducted my research outside of the facility in which I work. I had an obligation to protect the confidentiality of the participants and therefore the following steps were taken:

- I used numbers on the audio tapes to identify the participants rather than their name
- The transcriptionist did not know the identity of the participants
- I used pseudonyms in the text of the research
- The audio tapes and transcripts were kept in a locked filing cabinet and only I had access.
- I did not reveal the name of the institution in which I conducted my research

- The facility staff did not know who took part
- I did not include my former neighbour

All the informants were asked to sign a consent form (see Appendix 3). I reviewed the consent form with each participant and they received a copy. Participants were made aware that they were free to withdraw from the research at any time.

Summary:

I used an interpretative design as my paradigm because I was interested in the *lived experiences* of the subjects in this study. I used a framework of phenomenology. Interviews were transcribed verbatim, and statements of significance were extracted. Rigor was addressed by ensuring credibility, transferability, dependability and confirmability. Steps were taken to protect the confidentiality of the participants and they were free to withdraw from the study at any time.

CHAPTER FOUR: DISCUSSION

This chapter describes the results of the four interviews with the participants. The purpose of the study is to provide a rich description of the participants' experiences. I have used the themes, the essences of the participant's experiences, as my heading in the first part of the chapter. Under each theme a brief description and interpretation is provided. I provided a summary of the description of the experience of the participants, discussed the dominant concept that ran through the core of the themes, made a connection to the literature, and lastly, provided a metaphor as a way of illustrating my interpretation of the experience of being an older woman providing care to a spouse in long term care.

The naming of the themes that emerged was arrived at from the question I kept asking myself: "what is going on here?" An article by Chenail (1997) was helpful as I looked for themes because it reminded me to focus on what my study is about throughout each step: "Research projects, especially qualitative ones, can become muddled and do get out of line because, when the richness of our curiosities meets the richness of qualitative data, researchers can easily become overwhelmed with the choices they have to make" (p.2). Four themes emerged: I know; being vigilant; feeling obligated/being responsible; having purpose/playing a role. The names I gave the themes came from the participants words. For example, one participant spoke about "Obligation," naming the theme. Other participants described their experience of being obligated but did not name it.

Themes:

There were many similarities and common elements in the experience of the participants despite the difference in their ages (71 to 87), economic status and living situations. Love (1994) outlines a number of key elements to be considered while identifying themes: repetition within and across interviews, levels and nature of affect, historical explanations, descriptions and interpretations; explicit and implicit interpretations; and serendipity or behaviours that are different or unexpected. The eight electronic files created from categorizing the statements of significance discussed earlier were printed off, thus becoming paper files. As I read the data bytes in their dedicated categories I continued to ask myself, what is going on here? At this point in the process, the analysis involved using coloured pencils highlighting themes.

Theme 1: I Know

The theme of 'I Know' is very central to understanding the experience of the participants. Several statements made by the participants indicate their insider knowledge of their spouse. For the participants the knowledge that they have about their spouse defines their unique relationship with their spouse. The inside knowledge is divided and has two timeframes pre-admission, a time when failing health became apparent, and post-admission. Three areas of expertise were present: knowing when something is wrong; knowing what the resident wants/needs, and knowing what the resident is trying to say. Also related to the theme of I know was the ability on the part of the spouse in care, despite memory impairment, to know and recognize his caregiving spouse. This was very important to the participants. Therefore, I have included it under this theme.

Knowing when something is wrong

“I knew Jim was losing it and I was on pins and needles whenever we went out in the car and I thought, you know, I’ve got to get his license taken away from him” (Shawna)

“I knew a few years before that his memory was starting to go” (Shawna)

“We were going down the Pat Bay Highway, and I realized that he wasn’t driving like he usually did” (Mary)

“I said take his blood pressure something is wrong” (Mary)

“I noticed his teeth had fallen out” (Mary)

“I said I think he is depressed” (Shawna)

“He had a cast put on the wrong foot, he kept showing and showing, and we kept telling, look how swollen that is, and nobody agreed” (Kathleen)

“I know when he is different” (Pamela)

Knowing what her spouse wants/needs

“If he is toileted every four hours, he is the happiest man” (Kathleen)

“I said he doesn’t need it (referring to a medication). He was doing better before this! He is off now and doing fine” (Pamela)

“When we arrived at xxxxx, the dietician said, “xxxxx said Mr. (blank) had to have pureed food”. I said no way! All he needed was...because of the Parkinson’s, he couldn’t cut with a knife. Anyway he is back to regular...I said I don’t puree everything for him when he comes home” (Pamela).

Knowing what the resident is trying to say

“Because I know what he is saying, and they don’t...so I just make it easy for him. It saves time”(Pamela)

“ Because of him not being able to speak, and not being able to ask for anything. So we are there to help, you know” (Kathleen)

Resident in care knowing/recognizing his caregiving spouse:

“He still knows me at the nurse’s station” (Mary)

“He still knows me” (Shawna)

“He is so happy when I come in there---he just lights up like a Christmas tree”(Kathleen)

“I just think the sight of me—you know? He knows that he has somebody to talk to” (Pamela)

The knowledge that the women possess about their spouses is indicative of the unique relationship that they have with their spouse and for the women entrenches their connection to their spouse. Not only did the women in this study speak about the knowledge they had about their spouse and the importance of this to the care of their spouse but also, they said that despite varying degrees of cognitive impairment, their spouse knew them. For the participants having their spouse know them when they may not remember someone else due to dementia was an important experience. There was a certain pride and joy in telling me in the interviews that their spouse still knows them.

Theme 2: Vigilance

Part of the participants’ self-described role is to be vigilant. During the first phase of analysis, I was referring to this as a “watchdog role”. The experience of providing care for their spouses includes ensuring their spouse is having his care needs met. The participants may no longer be able to carry out all the physical care required by their spouse, but they can ensure that the staff provide the care.

Vigilance:

“I want to make sure that everything is okay, that he is looked after” (Mary)

“You see you have to keep on top of things” (Mary)

“I make darn sure the nurses have appointments in the book” (Mary)

“But they know me-they know I don’t over-look anything” (Mary)

“Well, I knew she didn’t because I was there all the time with-I didn’t leave him for a second (Kathleen)

“I stand up for his rights” (Pamela)

“I think it is really important, I think, I can see for myself” (Pamela)

“So, I feel that if you are not there to catch things, it becomes a problem” (Kathleen)

“And I know that it is getting done, because if I didn’t do it, it was neglected and not done” (Kathleen)

“I want to protect him, because he can't do it himself”, (Kathleen)

“They will bypass somebody yelling, you know. It is like they don’t hear, you know? The light is blinking, and the person is yelling in their room. You know, they will say, “okay we will be there in a minute so an hour goes by...” (Pamela)

Being vigilant and ensuring that the needs and wants are addressed is very important to the women. They believe that the staff are aware that they are watching and therefore behave accordingly. There is a concern that if they perhaps were not attending to overseeing the care it may not get done.

Theme 3: Obligation

The time participants spend at the facility varies from every day to three times a week. It was very clear to me in the interviews that each participant believed that it was important to go to the facility often. Going often allows the women to be vigilant as discussed previously. The participants feel obliged to go; it is seen as a duty. The theme of “obligation” is taken from a direct quote of one of the participants.

Obligation:

“You feel it's a duty, but as I said, I rather enjoyed it because it's good for me”.(Shawna)

“No, it’s just doing what I would feel I would need if I was in that position. You have to put yourself almost in the position of, “If I was there, what would I need?”(Kathleen)

“When he couldn't do it any more, he needed me to take over. I would say to people, "He looked after me for fifty years, now I am looking after him", and that is about the size of it (Mary)

“Well in a certain way -- so you sort of feel that you are obligated to do that, because of him not being able to speak, and not being able to ask for anything. So we are there to help, you know” (Kathleen)

Well, it was difficult, sure -- I felt responsible for him. As Jim used to say, the nearest thing he used to give me as a compliment was, "We make a good team!" (Shawna)

Well, when I married, I ‘married in sickness and in health’. Too old-fashioned as hell, but... (Shawna).

“It's a duty. Not that I don't -- but sometimes I get up and (inaudible) today I would like to stay in bed! Spend the rest of the day in bed, you know? (Shawna)

“For me there are a lot of things I'd rather be doing! (laugh). You know, like just staying home. I would love just to putter around and visit with Sandy (daughter), do a few things like that”. I guess I love him, and I feel sorry too. (Pamela)

“Because I think they get used to you coming in, that once you stop, if you don't go for two or three days, they think you may not like them anymore—I don't know what goes through a patient's mind” (Pamela)

The women use words like obligation and duty when discussing why they go to the facility. One of the participants talked about feeling responsible and another felt sorry for her spouse. There is also a notion of commitment; as one participant said, “I married in sickness and in health.”

Theme 4: Roles /Purpose

While the participants spoke about obligation and duty they also spoke about their role, the things they do for their spouse, as well as how they felt about what they do. As I reviewed the statements of significance that I had moved into a file called “feeling” and another called “activities,” the theme of role/purpose emerged. The participants noted that it was like a job and, as one participant noted, “without pay.” The experience of providing care not only felt like a job, but another participant reported feeling exhausted.

Statements were made by the participants not only describing what they do and how they feel but also the conflict that arises between their role and that of the professional staff.

What they say they do:

“I take him down for tea and I take him on Mondays to play Jackel” (Shawna)

“...well they would give me Boost and I would take him outside and I would try to get him to take Boost, or take a chocolate bar ...trying to get him to eat”(Shawna)

“I do his laundry. I used to make all his shirts, and I like to iron his shirts, and I am fussy about his clothes. I like to do it and it’s nothing to do. It’s nothing to do it so I do his laundry and sometimes I go in and the night staff weren’t aware of this, so I have got signs all over, wife does laundry”(Mary)

“So everyday, I take him down to the xxxx, yes we have tea or coffee and goodies every afternoon. I go in. He is just finishing lunch, and I wheel him around, outside if it nice, inside if it isn’t. He just likes to be moved around” (Mary)

“And I take a big album and go through the pictures with him and I certainly try and spend at least 15 minutes or half an hour of the time ...” (Shawna)

“Sometimes I will talk about things that we did and, of course, he doesn’t remember a lot of them, and he’ll say, “did we do that?”, and I will say, Yup! We had a good time. We did a lot of traveling, and sometimes I will take a few pictures of when we were in Mexico” (Shawna)

“Reminisce with him, although he can’t...he looks at me, you know, and sometimes a glimmer comes back and he remembers when you tell him...but I try to keep his mind as active as I can”(Shawna)

“I do crossword puzzles with him. We do at least one crossword puzzle” (Pamela)

“And then I just take him out and walk around the hospital where it is flat” (Pamela)

“I think it is keeping him mentally alert, as much as I can. And then we watch TV together, different things. Certain days he has trouble feeding himself, so then I help out” (Pamela)

“Yes I put after shave on him and things like that, and it makes him feel good. The other day I asked him, Did you brush your teeth this morning? And he said, “I can’t remember”, and so I said, Let’s not take any chances” (Pamela)

“Well, I always have something to take up...like he gets a lot of phlegm and somebody mentioned that if you drink pineapple juice, the acid in the pineapple juice breaks down

the phlegm...so I had to go to Thrifty's, get ten cans of pineapple juice, and now they are all gone, so I have to go again"(Pamela)

"I do his warm-up exercises, too...because the physiotherapist is only there a half day, or something...two or three times a week, and that is all. So it takes about 15 -20 minutes."(Pamela)

How they feel about what they do

"Well I like to be with him. I enjoy being with him, actually. You know it's funny I built my life around spending time with him. As I say he looked after me for fifty years, and now I am looking after him" (Mary)

"When I come home in the afternoon, that is it, and I think that is why I didn't work out with my student, because I was too tired to get a...I eat a lot of salads, and she didn't go for this, and I don't do a lot of cooking now" (Mary)

"And I guess I get a sense of, not important, but a sense as if I am still a little bit useful in some way" (Shawna)

"When I go there and I take him around and do little things for him, I am tired when I come home, I'm exhausted. (Kathleen)

"If you are very close with your partner, it's just like being broke in two when he is gone -- you have a very close connection, right? It is hard to explain -- you have to live it (Kathleen)

"But I love to help" (Kathleen)

"It is not easy. Yet I love to go to be of help, but it is as though I am wrapped up completely there, instead of thinking to do things for myself" (Kathleen)

"I didn't realize I was losing a lot of weight too, and I didn't have time to think of myself, right? Myself meant nothing" (Kathleen)

I just do it without thinking. You know, it's just automatic. I think I have done it for so long. It's become my job! No pay (Pamela)

"I think just the sight of me, you know? He knows that, okay, now he has somebody to talk to...not that he talks very much" (Pamela)

Role conflict:

Having a role and purpose also led to the women experiencing conflict. This relates to the notion of expert and who knows the resident best. This theme represents the frustration

that the participants felt/feel when their knowledge and expertise of the needs of their spouse is not acknowledged.

“It is an awful thing and you don’t realize until you go through the same thing, how you suffer from coming in, seeing it was the other foot and nobody is listening to you. It’s like a child when they complain” (Kathleen)

“And it was the nurse at the time—if I would tell her it was the other foot, she would just say “No! Not Again!” and she would turn her back, you know” (Kathleen)

“Some of them tell me, “we are so glad you are coming”, or the nurse will even say thank-you, Kathleen, for doing this”. Maybe some of those who didn’t look after him so well didn’t like to see me around. (Kathleen)

Two participants talked about conflict in the role of decision-maker prior to placement:

“No he is not going there...he will not be happy there. She said you have no choice. How dare you, I said, watch me! I do have a choice, and he is not going.(Mary) (Conversation with the liaison nurse in the hospital)

“I didn’t want him in the system but they saw the writing on the wall” (Mary) (Speaking about the doctor and her son)

“There was a committee—I don’t know---- there must have been about twenty people around a table, and I guess they were social workers, and doctors, and nurses, R.N.’s----I didn’t know any of them. They sat me down. They didn’t invite Tom to come, just me. And I said, well you didn’t need a meeting. You are telling me. You don’t need me. You have already made the decision. They were not asking me my opinion. They were telling me what they were going to do and he couldn’t come home.” (Pamela)

This theme of role and purpose was not just about the experiences of what the women do, for example a listing of activities but how they feel about what they do and the resulting conflicts that can occur because of their role vis-à-vis the staff in the facility.

The Description of Experience of Older Women providing care for a spouse in a long term care facility:

The purpose of the data analysis was to bring to light the experience of the participants in providing care for their spouses who reside in a long term care facility. Through a process of categorizing and analyzing the data four themes emerged; expert knowledge, vigilance, obligation, and role/purpose. The following description of being older and providing care to a spouse in a long term care facility is a result of integrating the themes of the phenomenon.

Table 2: The essence of the experience of older women providing care for a spouse in a long term care facility:

Women who provide care for spouses in facility care have insider knowledge of the needs and wants of their spouses. The insider knowledge includes knowing when a change in behaviour or condition has occurred. The insider knowledge also involves being able to interpret for their spouse when the ability to communicate has been affected. Having the insider knowledge also means having to be vigilant to ensure that professional caregivers are responsive to the needs and wants of their spouses. The women know that their presence in the facility means that their spouses will get the attention and care they feel is required. Having expert knowledge comes into conflict with those caregivers who have professional knowledge. The women felt that their opinions were not always listened to or appreciated. Providing care for a spouse in a facility is a double-edged sword. It provides women with a sense of being important and useful, and at the same time, it is exhausting unpaid work. Specific activities are carried out by the women that they believe have therapeutic benefits in

keeping their spouse's minds active; things such as crossword puzzles, word games, reviewing of old photo albums and reminiscence. These activities also keep them connected to their spouse, which is important. Going to the facility and providing care is best summed up by the following statement that was a response to my question of what would happen if you did not go; "I think he would be a recluse: he stays in his room anyway but he would just be there and disintegrate".

The Dominant Concept: Contradiction

The dominant concept that runs through the description of the experiences of the participants is the notion of contradiction. It appears to me that the participants are dealing with their conflicting needs around the care of their spouses and the tensions that exist between their notions of care and that of the staff in the facility. I see three dichotomous streams that illustrate the contradictions and provide structure to my interpretation of the experiences of the participants, and they are as follows:

1. Inability to Provide Care/Continuing to Provide Care

- "I was very relieved, because I knew I couldn't cope. In fact, it was my son and the doctor who said to me we've got to place him in care"(Mary)
- "so he got scraped on his legs badly...So, I dress that—not that I have to, but the nurses know I do it well, so I do it once a day"(Kathleen)

2. Exhausting Job/Sense of Purpose and Contributing

- “When I go there and take him around and do little things for him, I am tired when I come home. I’m exhausted” (Shawna)
- “I just do it without thinking. You know, it’s just automatic. I think I have done it for so long. It’s become my job! No pay” (Pamela)
- “And I guess I get a sense of, not important, but a sense as if I am still a little bit useful in some way” (Kathleen)
- “It is not easy. Yet I love to go to be of help, but it is as though I am wrapped up completely there, instead of thinking to do things for myself” (Kathleen)
- “I like to relax in the evening because I am tired; well, I wouldn’t be happy if I wasn’t”(Kathleen)

3. Experienced Caregiving/Professional Caregiving

- “He had a cast put on the wrong foot...and he kept showing and showing, and we kept telling. Look how swollen that is, and nobody agreed...it was like talking to a brick wall, and they left it on for almost three weeks, and then the nurse...she called me and said, I have an apology to make: you were right, it was the other foot” (Kathleen)
- “I stand up for his rights, and I know when he is different. They don’t”(Mary)
- “I noticed his teeth had fallen out. He has a full top upper and a half denture and I said, what happened? And nobody knew. They never noticed” (Mary)
- “Nobody is listening to you. It is like being a child when they complain (Kathleen)
- “I just felt like a little kid sitting with all these doctors, and I didn’t know who they were. I knew the news wasn’t going to be very good” (Pamela)

1) Inability to Provide Care/Continuing to Provide Care:

This first dichotomy sets the stage for what I see as the ongoing contradictions in caring for the participant’s spouse in facility care. The inability to provide care at home and the subsequent placement of the participant’s spouse is a time of actualizing a situation that is required but not desired. There are three elements within this dichotomy that I will address: individual care needs versus institutional care needs; the participant’s

care activities; and the feelings the participants have for their spouse and their commitment to their spouse.

Individual Care Needs versus Institutional Care Setting:

There exists a duality in needing care. The experiences of the women illustrate a duality not only in care needs for their spouse, individual care versus institutional care, but in their response to their spouse's need for institutional care. Placing a loved one in a care facility is a very difficult and challenging decision for families to make, and many studies indicate that it is particularly difficult for spouses (Kramer, 1999).

Prior to the participant's spouse entering facility care all four participants provided some level of care. This care ranged from close monitoring and arranging community services, as in the case of Mary and Shawna, to active hands-on personal care including bathing, lifting and physical therapy such as that carried out by Kathleen and Pamela.

In the interviews, the women spoke about the time when their spouse had to go into care. For one of the participants it was both a time of relief and dread, as she did not want her spouse in the system. Being relieved about facility placement and at the same time not wanting her spouse in the system demonstrates the tension between often competing needs. Kathleen would have deferred placement but, as in the case of Mary, family intervened. Kathleen reported the following:

Then he got the call here to go to the lodge, and I wasn't going to let him go, but the son was here from the prairies when I was getting the call, and he said "mom, let go!", and I guess they could see they could see I was weakening, because I had a cancer operation and a heart attack after that."

Kathleen wanted me to know that if the decision had been up to her alone she would have kept her spouse at home longer. Ryan and Scullion (2000) found in their study that “families felt a need to justify their decision by emphasizing how friends and other family members agreed that they could not continue with home care in the interests of both their own and the older relative’s health” (p.1187). Kathleen’s experience of having family intervene in the decision making is not unique

Ross, Rosenthal and Dawson (1993) suggest that “the decision to relinquish care to professionals is a difficult one because of the intense and often exclusionary bond between givers and receivers of care. This is particularly so for spouses” (p.1532). Two of the participants viewed the placement of their spouse as a separation.

Pamela felt she had no choice but to have her spouse transferred into placement as the system was pushing for it. “They weren’t asking my opinion. They were telling me what they were going to do and he couldn’t come home. But, if I did take him home, they would wash their hands of him.” Pamela’s experience is not unique: as Ryan and Scullion (2000) found in their study, “Family carers complained that they were given inadequate support from health care professionals and often had no choice in the decision-making process” (p.1187).

As was the case with Kathleen, health issues played a part in Shawna’s decision to place her husband. Shawna commented that the decision to place her husband was “very, very difficult. I had put him in prison, and you know, those were difficult years but I also realize that I have to stay healthy myself”. In the interview, Shawna talked about wanting to go into placement with her husband as her own health was failing. She was denied this and ended up going into supported living. In what was a poignant moment in

the interview Shawna described this experience as a “forced separation at the end of our marriage just like the forced separation at the beginning of the marriage” due to the war.

The transfer of the participants’ spouses into long term care was based on several factors and influences: 1) increased care needs of their spouse; 2) the health of the participants; and 3) the opinions of family and professionals. Needing institutional care and wanting institutional care are two different things. For the participants, having their spouse go into care was very difficult but they did not feel they had a choice.

The need for institutional care has not precluded the participants from continuing individual care within the institution. The participants all continue to provide care to their spouses after placement, bringing with them their own views and notions of care and making this fit within the new system of care.

Care Activities:

While unable to continue providing the care at home for their spouses the participants do participate in the care of their spouses in the institutional setting. Continued provision of care on the part of caregivers is not uncommon (Zarit, 1998). “During visits, they typically provided some of the same kinds of help they did in the home: for example assisting with dressing or feeding. In other words, functionally and emotionally, they were still caregivers” (Zarit, 1998, p.9). The following list of activities is not exhaustive but does highlight the types of tasks that the women engage in with regard to caring for their spouse:

- Shaving
- Feeding
- Warm-up exercises

- Wound dressings
- Transporting to and from activities
- Hand and face washing
- Teeth brushing
- Administering medications
- Massaging
- Transportation to medical/dental appointments

The care activities that the women engage in that do not involve physical care are:

- Advocacy
- Interpreting

Kathleen would like to provide more care if she were physically able. She states: “I would do anything if I could get him onto the toilet myself, because I used to do it before, and then there was no problem”. This statement not only illuminates activities that this participant engaged in prior to placement, toileting her husband, but the issue of residents in the facility needing to wait until staff is available.

As mentioned earlier, not all the participants engaged to the same extent in the physical care of their spouse prior to placement, nor do they now after placement. The activities that are common for all the participants both before and after placement are those involving socialization and getting their spouses to and from activities. It is not unusual for families to engage in social activities that enhance the wellbeing of their institutionalized family members (Keating, Fast, Dosman and Eales: 2001). Keeping their spouse active is viewed as keeping him healthy. Before placement, the women would take their spouses to activities such as lunches out or shopping like Shawna, or, as in the

case of Mary, arrange for her spouse to attend the adult day centre at a local facility. Statements like, “I kept him going” (Mary); “those that keep active, I think they keep young”(Shawna) and “I tried to keep him interested as much as possible” (Shawna) illuminate the importance the participants put on activity and socialization.

Mary has private help to take her place when she is not going to the facility. “Tuesday afternoons, when I don’t go in, I have a lady who takes him down to the xxx xxx for whatever is going on, and wheels him around for a while” (Mary). Getting their spouses out of their rooms and out and about is common for all the participants. They walk outside on appropriate weather days or inside when the weather is not conducive; as one of the participants stated “I just take him out and walk around the hospital where it is flat in the hallways” (Pamela).

Memory activities are a task that all the women participate in with their spouses. These activities involve, for the most part, one-on-one time with their spouse. The intent of these activities came as a surprise to me, as I had no previous knowledge or ideas about the intention from my experience working as a social worker. These activities are purposeful, selective and intentional attempts at maintaining a connection with their spouse. They are also deliberate attempts at maintaining brain function. As Shawna said,

“I try to keep his mind as active as I can, because they say that, from what I have read, that it is better for them that they progress slower”. “I take a big album and go through the pictures with him and I try to spend 15 minutes or half an hour of the time”.

Pamela also talked about the memory mind activities; “I do crossword puzzles with him. We do at least one crossword puzzle. I think it is keeping him mentally alert, as much as I can”. These activities are “value added” which are often rendered invisible.

Feelings and Commitment:

While the women spoke about feeling a sense of duty or responsibility they also spoke about loving and missing their spouse. Kathleen explained: “And it is like, if you are very close with your partner, it’s just like being broke in two when he is gone -- you have a very close connection, right? It is hard to explain -- you have to live it”. During the interviews, two of the participants became very teary when talking about placement of their spouse and missing them. Having their spouse go into a care facility was not an easy decision for any of the participants and being in agreement with the need for placement did not make the placement of their spouse easier.

All of the participants engage in care activities, and there is a large focus on quality care tasks such as socialization and memory. By continuing to participate in care activities the participants help to individualize the care for their spouse in the institutional setting. The participants can no longer provide care at home to their spouses, either because of the increased care needs of their spouse, or because of their own health concerns. Yet, they still continue to be very engaged in the ongoing care needs post facility placement.

2) Exhausting Job/Sense of Purpose and Contributing:

The second concept is a paradox that describes one facet of the experience of providing care for a spouse in a facility. On the one hand the participants spoke about being exhausted, that their experience of continuing to provide care to their spouses is a job, an unpaid job. One particular participant spoke about coming home and getting into her pyjamas at 4:30 and just watching T.V. because she is too tired to do anything else.

On the other hand, the women spoke about feeling like they were still useful. The following are the words of the women used to illustrate the paradox:

It is automatic/it's my job (Pamela)

Exhausted/useful (Shawna)

It is not easy/love to be of help (Kathleen)

Tired/happy (Mary)

Zarit (1998), and Zarit and Whitlatch (1993) have written extensively on the effects on the caregivers of family members placed in facility care. The focus has been on the stress levels and the depression experienced by caregivers after placement. Summing up his research Zarit (1998) states:

When we compared caregivers who placed their relative with those providing continuing care in the community, we found that the placement sample reported decreases of subjective stressors directly related to care routines: such things as feelings of overload and role activity. At the same time, new stressors emerged, such as financial strain over the cost of the nursing home. Visiting was stressful for some caregivers. For others, learning how to relinquish care and to interact with nursing home staff was difficult... In sum, while some stressors were diminished, others emerged. (p.10)

In her research on wives and caregiving, Perry (2002) focused on the positive aspects of caregiving. Perry states:

To allow for positive aspects in caregiving does not in anyway negate how difficult, burdensome, and stressful the experience is: rather, it suggests that burden may not always be the main focus and may not have primary meaning. Other researchers have found that positive themes can be identified along with burdensome and painful descriptions of caregiving" (p.314).

While the literature identifies the negative effects of caregiving especially for women there is also research that finds positive effects for the provision and receipt of care (Davidson, Arber and Ginn 2000). Caring is a double edged sword for the

participants in my study that takes a toll with regard to energy and time, but one that also provides a sense of purpose and connection.

During the interview process, I was able to note the intonations and expressions used by the participants. These elements of communication allow for a greater understanding of the meaning for the women. For instance, the participants became animated and excited when relaying to me that their spouse recognizes and responds to them when that same spouse may not be able to recognize other family members or friends. The participants have a unique relationship, a spousal relationship that is not only important to these women but one that they want to maintain. The participants manage to maintain the special relationship they have with their spouses in the facility and are also able to derive some satisfaction and positive benefits. Examples of the positive aspects of providing care for their spouse was best illustrated when Shawna described feeling a little bit useful and when Kathleen smiles while telling me how she loves to be of help.

The participants provided various levels of care for their spouses prior to placement and continue to provide care post placement. There are common caregiving activities that are engaged in by the participants. The level of involvement in the care of their spouse leaves the women exhausted. The women however, also experience a sense of purpose and usefulness.

3) Experienced Caregiving / Professional Caregiving:

The phenomenon of providing care to a spouse in a long term care facility involves engaging in care in a foreign domain. The neo-liberal idea of the professional as the expert (Peterson, 1996) plays out in the care facility. The professional as expert with primary responsibility within the facility is in contrast, I believe, to the social policy of recent times that focuses on the family, primarily women, as providers of and responsible for the majority of care within the home. The move to care in the facility does not, as discussed previously, preclude or stop care provision on the part of the participants. However, it does bring a whole set of new issues and new relationships that need to be navigated.

The move to placement, while seemingly a handing over of care, in reality is not an abdication of care on the part of the participants. The participants are still very involved in the care of their spouses, as stated earlier, carrying out a number of tasks. The participants not only navigate the waters of the facility but also negotiate and build relationships with the staff in order to ensure the care they see their spouse requiring is provided. The participants are not only extra hands in the care of the resident, for example, helping with feeding and grooming, but they also act as negotiators and advocates. The participants bring years and years of knowledge and experience to the facility.

The participants have inside knowledge about the care needs of their spouse and the staff have professional knowledge. Harvath, et al. (1994) refers to these two types of knowledge respectively as local and cosmopolitan. Local knowledge is idiosyncratic

knowledge that families have about each other. Cosmopolitan knowledge is the universal knowledge that professionals bring to particular situations (Harvath, et al. 1994).

Having their insider knowledge taken as seriously as professional knowledge was for some of the participants a job in and of itself. The participants experienced some role conflict, especially around knowledge of the resident and needs of the resident. Who knows the resident best and who knows what is best for the resident? Moreover, the transition to the facility and establishing relationships with staff was at times a bumpy road. As Ejaz, Noelker, Schur, Whitlatch and Looman (2002) state: "Research suggests that family caregivers of institutionalized elderly sometimes undergo a stressful transition from primary caregiver to visitor and from an insider role in the caregiving process to an outsider role" (p.369).

According to Mary, "you go in there and you don't know anything of the routine, but by gosh, you learn". When Kathleen said, "Nobody is listening to you, it's like being a child when you complain," she was describing her initial experience with the facility. For Kathleen, the first few weeks were very difficult. Her spouse had a fall resulting in a fractured ankle that subsequently resulted in the wrong foot having a cast. It took her three weeks to convince staff that something was wrong. She was able to interpret the flailing of her husband as pain rather than difficult behaviour as was the interpretation of the staff. Kathleen says the transition period was "not a good start...no, not a good start".

Despite difficulties in the transition to the care facility, all the participants reported that they are happy their spouse is at the present facility. This facility is relatively new, has private rooms and has a particular social milieu that is fitting for the previous experiences of the residents. There are long waitlists to get into this facility, and

two of the spouses were in other facilities while waiting for a bed at the present facility. Being happy with the facility is evidenced by the following statement by Mary "...these nurses are so good; they love him at the xxxx" and by the emphatic way the participants told me they were not complaining about the staff, although they acknowledged that staff shortages and the indifference of some staff members affect care.

Ejaz, Noelker, Schur, Whitlatch and Looman (2002) say that when a poor relationship exists between staff and family caregivers the family caregivers often report the quality of care in the facility as poor. The following comments illustrate this point: "I don't know why they are there, some of them. And I am not being facetious. It's the truth. They will bypass someone yelling -- it's like they don't hear"(Pamela); "he doesn't want anything else, but there are some that would leave him all the while until another shift comes on, and then he gets very upset because he holds back"(Kathleen).

The participants engage in what at first I called the "watch dog role" and then revised to be coded as "vigilance". The participants ensure that their spouses get services by either doing it themselves or ensuring the staff provides the care/services required. There is a sense on the part of the participants that if they were not watching, being vigilant, then it is possible, due to shortages of staff and the rare indifference on the part of some staff, that things would get missed. Kathleen spoke about her husband's experience at meal time: "they will give him things that are closed, and they won't open them, even when they bring things to him in his room—until I come and open the glass that is pasted shut, or cellophane on top of some food---he can't open that. So it seems if I am not there, it just stays". The concern that the participants have about not being vigilant

is summed up best by Kathleen when she described those residents that do not have family members who come to visit as “they are quite neglected at times.”

The participants have long standing relationships with their spouses and know when the behaviour or health status of their spouse is different. Having their observations of their spouse acknowledged by staff is important. Two of the participants discussed reporting differences in their spouse’s behaviour that were not picked up by staff because of the lack of historical knowledge. Shawna picked up on depression and Mary realized a difference in energy level that was due to low blood pressure. For Mary and Shawna the response from the professional experts was accepted and acted on, resulting in the participants feeling important and vital to their spouse’s care. One negative encounter was reported by Kathleen who, when reporting for the third or fourth time that something was wrong with her spouse, was greeted with “No! Not again!” And the staff person turned her back on her. In recounting this experience the participant became visibly upset, and I could see she had not gotten over the feeling of being dismissed or that what she had to say was neither important nor wanted.

Several of the participants spoke about the importance of the staff knowing that they remain watchful with regard to the care provided to their spouse. One of the participants stated that “They know I don’t let anything slip by” (Mary). Another participant commented that “maybe some of those who didn’t look after him so well didn’t like to see me around.”(Kathleen) This statement points to the tension that exists for some of the participants between themselves and the staff. The participants spoke about the steps they take to ensure better relations with the staff, and one of these involves providing food such as homemade cookies and baked goods for the staff. One

participant used her skills for fundraising and advocacy and has already secured items such as a large screen television for the facility. One other participant helps feed other residents who sit at the dining table with her husband. Another of the participants stated that helping feed residents “relieves the staff for other duties” (Mary). The participants spoke about these activities as helpful to the staff and as a way of relationship building. Getting along with the staff and being accepted is important to the participants.

The care activities that the participants continue to provide involve some personal care such as grooming, feeding and dressing. They also engage in providing quality care activities that involve socialization and memory. These activities enhance individual care within the institutional setting, focusing on well being, maintaining present condition or slowing down decline and keeping their spouse as healthy as possible.

The care provided by the participants is important work and viewed by them as an exhausting job. At the same time they derive a sense of purpose and sense of usefulness from their participation. The knowledge that they have of their spouses is valuable to the ongoing care. By being vigilant and participating in their spouse’s care they ensure that their spouse receives the individualized care they deserve. To this end they act as negotiators and advocates. The participants experience appreciation for their work in the facility, but they also experience tension and stress when their role brings them into conflict with staff.

Connection To The Literature:

Given what arose out of my study I have returned to the literature with my results to see if there is support for my interpretations. As stated earlier there is a plethora of research on caregiving in the literature; however, there is very little research on the

experiences of older wives providing care after placement. The majority of the literature that I reviewed focused on family involvement after placement, and most of those studies were quantitative. (Brubaker; 1987; Buckwalter & Hall; 1997; Ejaz, Noelker, Schur, Whitlatch & Looman: 2002; Friedemann, Montgomery, Mailberger & Smith: 1997; Friedemann, Montgomery, Rice & Farrell; 1999; Grubriun, 1991; Ross, Carswell, & Dalziel, 2001; Rudd, Viney & Preston, 1999; Yanamoto-Mitasa & Levy-Storm: 2002; Zarit & Whitlatch, 1992). Two of the quantitative articles looked specifically at spousal caregivers (Ross, Rosenthal and Dawson, 1993; Rudd, Viney, & Preston, 1999). I also reviewed studies that were qualitative (Duncan and Morgan, 1994; Kellett, 1999; Ryan, & Scullion, 2000).

While very little of the literature focused solely on older wives who are caregivers after placement or institutionalization, the findings of the studies do lend support to my interpretations within this study. The literature can be broken down into three categories: caregivers as visitors after institutionalization; nature and type of tasks that family caregivers carry out; and the relationship between family members and staff.

1) Caregivers as visitors

The fact that the studies refer to family members or spouses as visitors to the facility is interesting. Visitor is a term that conjures up the notion of a guest, someone who is transient, passing through or temporary. The term visitor does not invoke the idea of partnership in care. It is clear from the research that visiting spouses are more than visitors: arguably duration is tied to length of stay on the part of their spouse, but given the frequency of the visits to the facility I would argue that the caregiver is more than a guest. The fact that we put family caregivers/ spouses in the visitor category illustrates

the separation and division of care provided by spousal caregivers and professional caregivers. It illustrates a particular view of the family caregiver role.

Brubaker (1987) refers to long term care facilities as bureaucratic structures designed to deal with specific care tasks in a uniform manner. Lines of communication and decision making within bureaucracies are often carried out through a hierarchical chain of command. Families are not necessarily factored into the chain of command and therefore, by default are relegated to the visitor category, even though it is clear that the knowledge and information they bring are important to the care of residents (Brubaker, 1987; Buckwalter & Hall, 1987; Pratt et al., 1987).

The research refers to family members as visitors even though the same research also recommends that families and professional caregivers work together in partnership. It would seem to me that if family caregivers are to be seen as partners in care, then perhaps the research should stop referring to them as visitors. The term 'visitor' may mean simply, that the person does not live in the facility, and therefore, the term is not incongruent with the notion of partner in care. However, residents in care facilities do have visitors that are not partners in their care and I think there needs to be a distinction. Family caregivers and particularly the participants in my study are involved in several activities and tasks that, I believe, would leave the term visitor in this instance malapropos.

2) Nature and Types of Tasks Performed by Family Caregivers:

The participants that I interviewed were involved in providing care for their spouses, which included physical care, such as washing, bathing and wound dressing; accompaniment to activities; engaging in reminiscence; advocating and interpreting; and

overseeing the care provided by staff. The literature is consistent with the experiences of the participants I interviewed. Pratt, Schall, Wright and Hare (1987) found “ The important responsibilities typically described for the family caregivers in the institution include providing information about the patient, regular visiting and outings, reminiscing, exercising with the patient, assisting with the implementation of care plans and providing continuing love and affection”(p.198).

Ross, Rosenthal and Dawson (1994) report that family caregivers provide care in a number of ways:

- 1) They monitor residents and report to staff when something is wrong.
- 2) They provide comfort care even going as far as providing nursing care.
- 3) They participate in decision making regarding treatment.

Friedemann, Montgomery, Mailberger and Smith (1997) grouped the activities in which they found family members involved into three categories. The first category comprised activities that involved maintaining connectedness to the family. Emotional bonds are maintained through visiting and regular updates on family events. Also in this category were those activities that were pre-existing and included physical care activities. The second category comprised activities that the authors saw as maintaining the personality and dignity of the resident, those activities that prevent rapid decline not unlike the activities such as crosswords and memory tasks that the participants in my study engaged in. The third category was the control or maintenance of control of the caregiving situation. These activities concern the protection of the residents including advocacy on behalf of the residents or any actions that compensate for less than ideal care.

The findings of Ross, Carswell and Dalziel (2001) are similar to those of Friedemann, Montgomery Mailberger and Smith (1997). They found that the majority of care by family members involves indirect care, such as advocacy. However, Ross, Carswell and Dalziel (2001) found that a minority of family caregivers performed technical tasks associated with personal care, and a minority of family caregivers reported monitoring and assessing medical treatment and medication use.

Friedemann et al. (1999) found that “due to their strong need to be with the resident and the extensive exposure to the nursing home environment, families who visited frequently desired a more intimate involvement best actualized by providing direct care and working closely with staff” (p.564). Further they state, “patterns related to family bonding and stability seem to be prerequisites for the motivation to be involved in all types of roles” (p.565).

In The Mosaic of Care, Gubrium (1991) referred to the family caregiver as an interloper in the daily affairs of the nursing home. He (1991) states:

Family members are to some extent like strangers on the premises, even while some have a habit of being there daily for extended periods of time. Strangers take stock of things in a way natives do not. Strangers do not take as much for granted. They inspect environs for what seems or does not seem right or routine, according to the sense of order they bring to them (p.122).

More importantly, he continues:

While some families may be considered lax in this regard in principle they are initially taken to have a special tie to the patient, signifying loyalty and protection. When the circumspection and concern of the stranger combine with advocacy, the interloper becomes a sentry of care, a potentially formidable intruder (p.122).

When I read this passage I thought about Mary, a participant that I would describe as a formidable spouse although I would not call her an intruder. Mary was very animated with power in her voice when telling me that “they know I don’t let anything slip by”.

Researchers such as Buckwalter and Hall (1987) and Brubaker (1987) view the knowledge that families have about their loved one as valuable. The role of family caregiver as provider of this specific knowledge is important to the bureaucracy in order to meet the needs of the resident (Brubaker, 1987). “Ideally, the family role in long term care is to facilitate linkages that will assist the dependent resident’s interaction with the nursing home bureaucracy and will buffer the effects of the bureaucracy on the resident” (Buckwalter and Hall, 1987: p.178).

When I analyzed the data of my study, one of my surprises was realizing the participants were purposefully engaged in reminiscence. As stated earlier my own practice had not revealed this purposeful activity. I also did not find any reference to reminiscence in the literature except for a brief mention in Pratt et al (1987) until I read Buckwalter and Hall (1987). They see reminiscence as something that family members can engage in that has a benefit to residents and at the same time can “provide relief to overworked, burned out staff members” (p.189). The authors take this one-step further, and suggest family members augment staff resources in the running of structured reminiscence therapy groups (1987). It would appear, that this takes the unregulated, social activity that family members engage in, and tries to formalize it and turn it into a medicalized, professional task. The participants engage in reminiscence intuitively knowing that it is helpful to their spouse, and it is also an activity that keeps them

connected. Having their spouse know them and respond to them was very important to the participants.

In their qualitative study, Duncan and Morgan (1994) reported, that when family caregivers described their caregiving it was not in terms of task, but in terms of purpose. “Family caregivers believed that the most important purpose of their own involvement in formal care was to preserve the older individual’s identity” (p.236). The participants in my study engaged in tasks like grooming and dressing that preserved the specific individual aspects of their spouse. Mary, for instance, continues to do her spouse’s laundry because she likes him to look sharp. Pamela shaves and grooms her spouse as a way of preserving how he liked to be presentable. Preserving and maintaining their spouses’ idiosyncratic way of being is important to the participants.

3) Relationship between Family and Staff:

The decision to place their spouse in a facility was not made lightly by the participants, and for three of the participants the decision involved input and direction from family and professionals. Making the transition into care also proved to be difficult for the participants. Part of the difficulty involves the adjustment to the facility itself and the relationship with staff. Several research articles in the literature speak to the importance of the relationships between staff and family caregivers.

The literature shows that family caregivers want to have their knowledge and experience acknowledged and considered, that is they want to feel respected (Friedemann, Montgomery, Rice and Farrell, 1999; Friedemann, Montgomery, Mailberger and Smith, 1997; Harvath, et al. 1994; Duncan and Morgan, 1994) and they

want to build relationships with staff as a way of ensuring that their loved ones receive the care required (Duncan and Morgan, 1994).

Kathleen spoke very emotionally, and her frustration with the staff who would not listen to her was very evident in the retelling of her experiences. This experience is consistent with the research of Friedemann, Montgomery, Mailberger & Smith (1997) who state:

Family interaction problems were cited more frequently than any others. The problems were related to two themes: problems with affirmation and problems with cooperation. Families expected to be heard, respected, and affirmed. Instead many cite problems leading to a perception of being ignored treated without sensitivity or respect for their concerns (p.532).

Duncan and Morgan (1994) in their study found:

The issue of how staff related to the caregivers themselves was by far the most frequently mentioned theme in the discussions of nursing home staff. These family-staff relationships operated at many levels. A common topic was how the staff reacted when family members relayed their knowledge about how to care for the resident. Although these family caregivers generally accepted that their role in making care decisions was distinctly secondary to that of staff, they also felt that the staff should take heed of their extensive experience with the resident (p.240).

The participants that I interviewed all spoke about the relationships they have with staff. Some experiences have been trying, like those experienced by Kathleen, but even Kathleen has built close ties with staff. These relationships are important and all the participants actively work at maintaining the relationships. This is done, as stated earlier, by bringing staff treats, helping out during meal times and by carrying out grooming and care tasks for their spouse that free up the staff. Building and maintaining good relations with staff, in part, is because the participants are social and want to be liked. This was especially true for two of the participants, who seemed to place importance on the staff liking and socialising with them. The participants, also want to maintain good relations

with the staff, as a way of insuring that they will take care of their spouses and perhaps pay attention to those little things that make a difference. The participants are aware that the limited staff and the nature of residing in an institution means that not all the residents get their individual needs met in a manner to which they were accustomed. This is corroborated by Ejaz, Noelker, Schur, Whitlatch and Looman (2002) who found that families believed improvements were needed in the amount of care provided to residents, the personal attention given to residents and the number of nursing assistants.

Gubrium (1991) says “while there is a tendency to homogenize, which is an organization’s way of rationalizing its activities, the organization produces diverse but inherent troubles because official roles come into conflict with biological particulars” (p.138). The routinization of toileting for example, does not necessarily fit with residents natural bodily functions and timing. By having good relationships with staff and ensuring, the staff knows they are vigilant; the participants can maximize the chances of their spouse receiving the individual care desired.

Duncan and Morgan (1994) found:

Looking deeper than the simple desire for a relationship with staff, family members often discussed their felt need to form a relationship with staff members as a way of having an active influence on the staff. As one put it, “We’ve come to the conclusion now that the purpose of the visit is to show the staff that you care. Along these lines, caregivers told how they provided care to their resident in a way that they hoped would be a role model for the staff. Family caregivers also intentionally gave positive

feedback to staff as a way of influencing staff to provide higher quality care for their resident (p.240).

While good relationships between family caregivers and staff may seemingly improve the quality of care for residents, the literature suggests that the contrary is also true. Ejaz, Noelker, Schur, Whitlatch and Looman (2002) found that there is a relationship between the families' perception of care and how well the family gets along with staff. Moreover, they report that "findings indicate that family members who perceived that significant improvements were needed in direct care had more negative interactions with other staff and gave more help with ADL to their relative"(p.379). My interpretation of the experiences of the participants I interviewed was that they engage in several care activities because 1) they recognize that there is not enough staff to provide the individual care required by their spouse, and 2) they also maintain a sense of purpose.

Metaphor:

Having described in detail and summarized the experiences of the participants with regard to providing care to their spouses, I have been thinking about what metaphor would best illustrate the experience. At first, I thought about the women being in foreign territory like immigrating to a new country with respect to their husbands' institutionalization. However, that metaphor fits only some parts of the experiences they described. I also thought that the experiences of these participants are not unlike the experiences of first going to school as a child. Whether you immigrate or go to school, foreign territory is being traversed.

The school metaphor seems more applicable in describing the experience of the participants as they themselves use the analogy of feeling like a student or as one participant stated feeling like she was in school. Going to school involves entering a new environment where someone else's expertise and knowledge takes precedence. Often younger students are seen as *tabula rasa*, blank slates that need to be filled with the knowledge and information that the institution sees as relevant. The a priori knowledge that the child brings to the school may or may not be considered significant. So too is it the case with the insider knowledge that the participants bring to the institution.

The student is expected to participate in the educational institution; however, boundaries, limits and schedules are set such that participation is structured, monitored, and evaluated. One of the participants applies a daily dressing to a wound on her spouse's leg; this she does with the permission of the staff because they know she does a good job.

When students enter the school system there is an expectation that a certain degree of trauma and difficulty will occur and adaptation may be required. The adaptation and adjustment are concentrated on the student rather than on the institution. The experience of the participants is also one of having to adapt to the institution. Mary spoke about her joy in being able to meet new families and explain the ropes. "And I love to sit and talk to a new wife, who has just come in...and I love to be able to give them some idea of the routine" (Mary).

The love of learning and the curiosity involved in learning on the part of the student can compensate for the structural nature of the educational system. Just as the love of learning can make a student successful, so can the love of a spouse and the

commitment to care for that spouse help to overcome the sometimes difficult situations arising in the facility.

One can argue that the intent of educational institutions is benign and provides a service to students. The institutions of care also provide a service and have benign intent. Service to me involves a provision of benefit to the receiver of the service. While I believe there is benefit to students and care facility residents and their families, I also believe that institutions are self serving or perhaps self preserving, and the bureaucratic nature of large institutions may at times leave little room for individual needs.

Students, like the participants are not powerless in the institution. Students do have agency. Student organizations at the post secondary level wield political power through alliances with other organizations and groups. Individual students do have some power demonstrated in the choices they make about where they will attend and what classes they will take. Younger students are more dependent on adults to be their agents. The participants can and do carry some power that, when used well (in the political sense), has influence and can bring about change. Mary for example was able to get a dental program funded for residents in the institution.

Educational institutions face budgetary restraints, and at times, go through periods of cutbacks. Long term care facilities have also faced periods of restraint and cutbacks, as well as facility closures, resulting in increased pressure on remaining facilities. Larger class-room sizes like fewer long term care beds result in increased stress for students/residents, teachers/staff, and families. Just as the slogan 'putting the "U" back in education' is apropos for education, so too is putting the "Care" back in long term care.

CHAPTER FIVE: CONCLUSIONS AND IMPLICATIONS

The focus of this study was the lived experiences of older women who continue to provide care to their spouses in a long term care facility. This interpretative study provided a full description of the experiences of the participants. In this concluding chapter I will revisit the assumptions that I had coming into the study as a framework for discussing briefly my findings and some of the surprises. I will present some implications for social work practice, spousal caregivers and residents. Finally, I will comment on the limitations of the study and implications for future research.

Assumptions Going into the Study:

The assumptions I had going into the study came from my work and family experiences. The findings in the study provide support for some of my assumptions and as expected the experience of the phenomenon by the participants uncovered several aspects that were not anticipated.

With regard to my first assumption, the literature (Hooyman, 1998; and Paoletti, 1999) provided evidence for the role that social policies play in maintaining and increasing the care provided by women, yet the participants did not refer to social policies as determinants or influences on their experience. The participants did refer to shortages of staff within the facilities as having some influence on the contributions they make to providing continuing care in the facility. The experience of the participants is based on the everyday practicalities (micro level) of care. What, if any, connections the participants have made to broader social policy was not exposed in any detail.

The literature indicates that women and families continue to provide care to their family members after facility placement. A number of studies, Ross, Rosenthal and Dawson (1993); Duncan and Morgan (1994) and Ross et al., (2001) to name a few, have discussed at length the activities that the family caregivers engage in with their family member in facility care.

Assumption number two is supported, as the participants engage in care activities because they do not believe the facility is able to provide the kind of care their spouse should have. The degree to which they participate varies and the types of tasks they carry out also vary. The participants also act as advocates to ensure that their spouse is receiving the care from others that they believe is required and they can no longer carry out. Participants expressed the view that without their help certain important care tasks would not be adequately provided.

The third assumption derives from my experience working in both acute and long-term facility care. Activities involving help with feeding and social events are helpful not only to the residents of care facilities, but also to the staff. Facilities depend on family members helping out especially with feeding residents, as this is a time consuming task. The participants in this study carry out activities that they acknowledge are helpful to the staff. One participant felt that if she were not there, then her spouse might be ignored because sometimes bells are not responded to in a timely manner. This also reflects on assumption number two above.

The fourth assumption that I had going into this study was that families provide care out of a sense of familial responsibility, and this assumption was supported. The participants in this study described having a feeling of obligation and having a sense of

duty. Participants also spoke about having a sense of commitment and as one participant said she “married in sickness and in health”. While there was a sense of responsibility influencing their participation in ongoing care there were other significant influences. Feeling useful and productive and having a sense of “caring” for their spouse is also a motivation.

Insights:

The experience of the participants in this study illuminated a number of activities in which they engaged. Physical activities such as escorting their spouses to and from social activities, grooming, laundry, wound dressing and exercising are carried out by the participants. Mental activities such as reminiscence, crosswords and word games were also engaged in purposefully and intentionally by the participants. This group of activities was not something I had any prior knowledge or experience of. It was very clear to me from the descriptions of the participants that they were deliberately engaging in this activity for a specific purpose, namely keeping their spouse’s mind as active as possible and preventing decline.

Another surprise to me was the level to which the nature of the relationship with the staff affected their experience of providing care. While it is not surprising to me, given my work experience, that role conflict would/could occur I had not realized the level to which the relationship between the participants and staff is taken as personal. The facility environment becomes the social milieu for the spousal caregivers and with that come all the social intricacies we experience with friends and family. Therefore being dismissed or ignored has a whole other dimension. It also was clear to me that the participants worked hard at maintaining good relations with the staff. This often involved

the bringing of food or special treats, and the helping with activities that clearly freed up the staff. One of the participants often has the staff to her home for a home-cooked meal. In part, my sense from the participants was that this not only enhances their relationships with the staff who become friends but it becomes a way to ensure appropriate care will be given to their spouse. As the literature indicates, the view of the relationship between family caregivers and the staff colours the perception of the care provided to the resident.

Limitations of This Study:

No research is ever complete, and in writing this thesis it became clear to me that if I were to do it again or if I ever engage in another study I would meet with the participants twice. While Sandelowski (1993) argues that the second interview/meeting may not necessarily improve the credibility or dependability of the study, I think that having had the participants read the transcripts or confirm my interpretations may have led to a better, richer description of their experience.

This study looked only at older women who had been in long standing relationships with their spouses. The findings may not be the same for spouses who have not been in long standing relationships or for spouses who have been married for a long time but do not have a loving relationship. The research was based on interviews with a small group of carefully chosen participants, resulting in an interpretation that is specific to those participants. Qualitative studies, such as the one carried out here, cannot be generalized to populations other than those in the study. Therefore, it could be argued that this is a limitation of the study. However, the findings of this study were compared to current research on spousal caregivers of institutionalized family members, and the findings fit into the context beyond the confines of this study.

Qualitative research allows for the researcher to be present in the research. By declaring my ideas at the outset and by bracketing my a priori knowledge and thoughts I tried to alleviate this bias. Nonetheless, the process of interpreting the data and linking this to the literature may have reflected investigator bias. The very act of interpreting data and making the links to the literature involves researcher subjectivity, so this may be seen as an inevitable risk or limitation.

The Study:

The phenomenological study that I carried out was an inductive process involving thematic analysis. I was looking for meaning, trying to get at the essence of the experience for the participants. Data were collected through unstructured interviews that were tape recorded and then transcribed. The data were read and reread, and statements of significance were extracted. These statements or 'data bits' (Dye, Schatz, Rosenberg, & Coleman, 2000) were then categorized into groupings. From the data emerged four themes: I know; vigilance; obligation; and roles/purpose.

By integrating the themes, the essence of the experience emerged and I was able to describe the experience. The dominant concept that ran through the description of the experience of the participants was the notion of contradiction. I discussed three dichotomous streams that illuminated the contradictions:

- 1) Inability to provide care/continuing to provide care
- 2) Exhausting job/sense of purpose and contributing
- 3) Experienced caregiving/professional caregiving.

From these contradictions came what I believe are helpful insights into the experience of older women who provide care to their institutionalized spouses, and this will have implications for social work practice.

While the majority of the literature that I reviewed focused on family caregivers rather than specifically on older female spouses, it does support my interpretations and findings. The research on caregiver visiting supports the level of involvement that was described by the participants. The nature and types of tasks outlined by the participants is found in the literature. However, the qualitative nature of this study adds a level of descriptive richness to the experience of providing care. The participants that I interviewed make the tasks of providing care appear three-dimensional. The literature supports my interpretation of the importance of the relationship between staff and spousal caregivers.

Implications For Social Work Practice:

As stated above, research shows that family caregivers, and in particular women, continue to provide care to their spouses after facility placement. The behaviour and experience of the participants in my study supports the research. Those women, who cannot provide personal physical care such as lifting and transferring, still play an active role in the care of the resident. Understanding the experience of the participants illuminates the issues that these women face, and this I believe is information and knowledge that is useful in building better relationships between staff and family caregivers that ultimately will have a positive effect for residents. The information and interpretation garnered from the experience of the participants has merit for social work practice and does, I believe, contribute to knowledge.

It has been my experience, that the work done by older women who provide care for their spouses in long term care, are depended on, and needed, in order to maintain and care for residents. However, this work is not valued in a monetary sense. Family members are often seen as outsiders and interfering in the care of residents, not to mention unreasonable and demanding. When the women are helping staff, their work is valued. When the women are engaged in activities such as advocating that come into conflict with staff they are seen in a negative light.

As budgets for health care have been reduced over the years and policies have been implemented that encourage care within the home rather than the institution, so have budgets within the facilities been reduced. However, unlike in the community, the role of families within the facilities is not reflected in policy and is, I would argue, invisible. While I do not believe that facilities should off-load care to family members as a means of budgetary saving, I do believe that we must recognize the valuable work and role family member's play. Acknowledging the contributions of these women and treating them as partners in care requires a shift in thinking. Treating caregivers' knowledge of the resident as valuable information helps in the provision of comprehensive care. Working with families as opposed to seeing spouses and other family members as visitors will, I think, reduce the amount of stress and conflict for both family members and staff.

Implications for Spousal Caregivers:

It was clear to me that the experiences that had the most impact on the participants were those that occurred around obtaining the care they felt their spouse required and the nature of the relationships they have with the staff. I believe that by creating partnerships with family caregivers there will be benefits for both staff and

family members. It was clear from the descriptions provided by the participants that the nature of the relationships with the staff had a great impact on them. Staff who seemed indifferent or dismissive added to the distress of these women. By creating partnerships in care, the relationship between staff and spouses may shift sufficiently to bring about an environment that supports both staff and spouse, and recognizes the contribution of both.

Seeing family caregivers, and spousal caregivers in particular, as partners rather than interlopers, providing a place for them on the care team and not just the obligatory space at the table during the yearly mandatory care review, should decrease the mistrust that can occur between staff and family caregivers. Developing partnerships with family may help in humanizing the bureaucratic nature of care facilities and transfer the focus of care from the standardized “one size fits all” to recognition of individual needs. This recognition of individual needs would increase the preservation of the dignity that the participants felt was important in caring for their spouse.

Implications for Residents:

This study was not about the care of residents in care facilities, but I do think that any steps taken to improve the relationships between staff and family members will have impact on the residents. Whether the benefit is realized because of decreased stress on their spouse or because the environment focuses more on individual needs, I think benefit will be felt by the resident.

Implications for Future Research:

In this study, I looked only at older women, and I think that it would be interesting to see if the experience of male spousal caregivers is different. Does the context of providing care to a female spouse in care change the experience and the meaning of the experience? Would I find that males continue to provide care to their spouses in care for different reasons? Would males for some reason have a different experience in the situation? Would males be listened to differently? Alternatively, is the feminization of care such that male caregiving experience would differ very little from that of females?

Another area of research interest is the experiences of staff in care facilities and their experience in working with family caregivers. Having a greater understanding of the experiences of providing care, whether you are staff or family, may provide broader insights that could enhance practice.

My curiosity in doing this study has been piqued with regard to love and commitment. Do spouses who love each other feel more committed and therefore stay involved post institutionalization? Does love ensure commitment? Can you be committed to your spouse in care and not love them?

The last area, but one that I think is important particularly for social work practice, is further research on the amount of care and type of care provided by family, and the institutions dependence on this help. I suspect that family care has increased over the last several years and that institutions are becoming more dependent on this care since the budgets in health care have been eroded over the last several years.

Conclusion:

It was clear to me in this study that the participants are not only actively involved ~~in the~~ care of their spouse out of a concern that the facility will not or cannot provide the services/care they feel their spouse requires, but these women participate out of a sense of duty and obligation, and because they love and care about these men. The participants feel a sense of purpose and usefulness. While public policy discourse can take up the argument as to who is responsible for care of the institutional elderly, the state or family, I think that there is a need for a discourse to take a look at partnerships in care. Arguably, women are socialized into providing care for children and family. However, the participant's experience in my study suggests to me that they have a place in the spouse's life. These women are staying involved out of ~~commitment~~ commitment and love.

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Centre on Aging University of Victoria

Appendix 1: Question Guide

Research Question Guide:

Part one, Demographic Information:

1. Name/Number
2. Age
3. How long has your spouse been in care

Part Two, Pre-placement Information:

- 4 .Can you tell me about the care you provide for your husband at home?
5. What was it like for you before your husband went into care?
6. What was the deciding factor that brought your spouse into care?

Part Three, Placement Information

7. What was the transition into a care facility like for you?
8. Why do you come as often as you do?
9. Can you tell me about the things you do for your spouse when you to visit?
10. Is there anything you do for your spouse that someone other than you could do?
11. Out of the things that you do for your spouse what do you think is the most important to him?
12. Out of the things that you do what is the most important to you?
13. What care task has been the hardest to let go of?
14. What is it like for you coming to the facility and being with your spouse

Appendix 2: Recruitment Poster

Caring For Others

A Study of Senior Women

Requests Your Help

If you are a woman seventy or over, frequently visiting your spouse, and are involved with his care I'd like to interview you.

I am a graduate student at the University of Victoria, in the School of Social Work, doing a graduate thesis under the supervision of Dr. Pat MacKenzie.

Participation is voluntary and confidentiality is assured.

Participation involves 2 interviews of approximately one and one half hours each.

If you would like more information or are willing to participate, please call Carmela Vezza 479-5743 (home), 652-7508 (office) or e-mail at cvezza@uvic.ca

Appendix 3: Participant Consent Form

CONSENT TO PARTICIPATE IN THE RESEARCH

Till Death Do Us Part: The Lived Experiences Of Women Over 70 who Continue To Provide Care For Their Spouses in Long Term Care Facilities

You are being invited to participate in a study entitled Till Death do us part: The Lived Experiences Of Women over 70 Who Continue to Provide Care To Their Spouses in a Long Term Care Facility. My name is Carmela Vezza and I am a Graduate Student in the department of Social Work at the University of Victoria. As part of the requirements for my Masters Degree I am conducting this research. You may contact me if you have further questions by phone 470-5743(h) or 652-7508 (w) or by e-mail at cvezza@uvic.ca. This research is being conducted under the supervisor of Dr. Patricia Mackenzie. You may contact her at 721-8036 or through e-mail at patmack@uvic.ca.

The purpose of this research project is to find out about the experiences of senior women who continue to provide care to their spouses after facility placement. It is the voices of the women that I want to hear. Research of this type is important because it will provide a richer understanding of the experiences of women with spouses in care. By engaging in this research I can bring the voices of women to the forefront and expose the meaning of providing ongoing care after facility placement. The contribution that this research will hopefully make is to a better understanding of why women remain involved with the care of their spouses after facility placement. This understanding may influence policies of care that may reflect recognition of the role these women play.

You are being asked to participate in this study because you meet the selection criteria. The selection criteria for participants is women over 70 who frequently visit the facility and are involved in the ongoing care of their spouses such as, feeding, bathing and dressing. You have been given my name by staff who think you meet the criteria for my study. There is no requirement that you participate in this study this is purely voluntary. Your participation in the study is confidential and no one at the facility will know that you are participating. I am interested in your experience as a caregiver that continues to provide care to your spouse in this facility. I am interested in what it means for you.

If you agree to voluntarily participate in this research, your participation will include two taped semi-structured interviews between 1 and 1.5 hours in length. The purpose of the second interview is to review with participants any analysis as a way of checking for accuracy. In order to assure myself that you are continuing to give your consent to participate in this research, I will review the consent form and ask you if you still consent before the second interview begins

The potential benefits of your participation in this research include insight into your own role in caregiving. There is potential for society to gain some benefit from this research in recognizing the contribution made by female caregivers. This recognition and insights provided may influence policies of care and the state of Knowledge.

Participation in this study may cause some inconvenience to you, including time. There are some potential risks to you participating in this research and they include the experience of feelings or emotions that you may or may not be aware of. You may stop the interview and cease your participation at any time. To prevent or to deal with these risks the following steps will be taken: 1) I will follow-up after each interview by phone to check how your involvement in the study has affected you and 2) I will provide you with a list of support services such as Caregiver Network, Elderly Outreach Service, Facility Social Worker or support groups. There is no cost to you for these services.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data, tapes and transcripts will be returned to you or I will destroy the information by rewinding the tape and shredding the transcript. If

you choose to leave the study you will not jeopardize the over all research. It is important that you feel just as comfortable in stopping as you do in participating.

In terms of protecting your anonymity Participants will be assigned a number. Names will not be used. The list connecting the names to the numbers will be kept in a locked filing cabinet and destroyed once the tapes have been transcribed and the second interview has been conducted. Only I will know who has which number. Participants will be asked how long their spouse has been in the facility and this potentially could be an identifying factor, therefore, I will only report a range of stay limiting the possibility of identification. The small number of participants in this study could jeopardize your anonymity.

Your confidentiality and the confidentiality of the data will be protected. Participants will be assigned a number such as "interview # 1". There will be no identifying information on the tape or transcript. Participants will be offered the tapes back at the end of the research and if they do not want them the tapes will be erased. The transcripts will be kept, for possible future use in a locked file cabinet. Other planned uses of this data include future research papers, presentations and articles. There will be no identifying information in the transcripts, as each participant will be assigned a number.

It is anticipated that the results of this study will be shared with others in the following ways; the results will be written in my thesis, which will be defended in an oral examination. Participants will be notified of the defense date and invited to attend. Attending the oral defense may be a threat to anonymity and confidentiality. Copies of the thesis will be in the library and available for public review. If participants wish I can meet with individual participants and review the results of the study

In addition to being able to contact the researcher [and, if applicable, the supervisor] at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4362).

CONSENT:

My signature below indicates that I understand the above conditions of participating in this study and that I have had the opportunity to have my questions answered by the researchers.

Name of Participant *Signature* *Date*

My signature below indicates that I agree to having my interviews audio-taped.

Name of Participant *Signature* *Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix 4: Transcriptionist Agreement of Confidentiality

CONFIDENTIALITY AGREEMENT

This certifies that I, *Elaine King*, commit to keep in strict confidence all information made known to me during the time (November 2003) I transcribed tape-recorded interviews conducted by Carmela Vezza in the preparation of her thesis.

The names of the subjects interviewed were not disclosed to me. The transcripts of the interviews have been removed from my personal computer.

Signed:

Name: *Elaine King*

Address: *8650 EBOR TERRACE, SONEY, B.C.*

Phone: *(250) 655-0228*

Date: *November 30, 2003*