THE EVER CHANGING CAREGIVERS EXPERIENCE

THE EVER CHANGING CAREGIVERS EXPERIENCE – A REFLECTION OF A NEO-LIBERAL HEALTH CARE AGENDA

By

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ABSTRACT

In the past few decades, health care costs for the elderly population due to their complex medical needs has increased dramatically, such that hospitals and community-based service providers are struggling to deal with this matter. Research is beginning to address how elderly caregivers cope and adapt to the ongoing changes related to their spouses' dementia.

The purpose of this research study is to gain further insight into how four elderly female spouses, who have had to place their husbands into a long term care facility, are still *caring for* (in a practical sense), *caring about* (showing love and affection) and *caring with* (reciprocity with the marriage) their husbands. Qualitative research methods were utilized to highlight their experience. The data was analyzed using a critical feminist perspective and institutional ethnography.

The findings of this study noted the incredible changes elderly wives have to endure as their husband's health and cognition continues to decline, within a long term care facility. The elderly women noted that their ability to *care for* their husbands was often unrecognized and in direct conflict with nursing home staff. Furthermore, the women discussed how they continue *care about* their husbands by showing love and affection. The women also noted that their husband's ability to *care with* them was predominantly non-existent. In addition, they discussed a change in their personal identity; married but living as a single person in the community. Finally, they commented on the lack of physical intimacy and the impact on their marriage. This study offers valuable insight into the ever changing experience of a few female spouses who continue to *care for, about* and *with* their husbands and provides suggestions for social workers to work them during this process.

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To Him be the glory forever and ever.

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INTRODUCTION

In 1991, Canadians over the age of 65 years numbered 3.2 million and, of those, 1.8 million were elderly women (Moore, Rosenberg & McGuiness, 1997). Slightly over 1.3 million were men (Moore et al., 1997). Between 2002 and 2007, "the number of people providing care to seniors increased by more than 670,000" (Cranswick & Dosman, 2008, p. 49). The aging population, especially those 75years of age and older who have chronic health conditions, need a considerable amount of assistance with Activities of Daily Living (ADLs), such as bathing, dressing, eating and transferring (Rosenberg & Moore, 1997). Health conditions the elderly face can include: Alzheimer's disease, heart disease, high blood pressure, back problems, cataracts, diabetes, effects of having a stroke and urinary incontinence (Moore et al., 1997). Though the list above is not exhaustive, the point is that seniors typically face multiple/complex diseases and health concerns throughout their aging years. Typically, the first level of care provision for elderly adults experiencing chronic health conditions occurs in the home. It is important to note, that when one person within a married couple becomes ill, the spouse generally provides care. Given the variety and difficulties often affiliated with these health issues, many elderly will no longer be able to remain in their home and will, therefore, require a higher level of care, namely care provided by a long term care facility.

At the same time, over the last 20 years in both Canada and the United States, health care costs have increased dramatically. As a result, health care services provided by hospitals are noting an intense pressure to balance their budgets and review existing care services (Economic Council of Canada, 1986; Bulmer, 1987; Szasz, 1990). In addition, seniors who have been admitted to an acute care hospital often cannot be discharged home because their health concerns exceed their own or a relative’s ability (if available) to care for them. Instead these seniors are deemed as needing a ‘lower level of care’; meaning they are waiting to be transferred to an alternate level/type of care such as a long term care facility (Ontario Health Coalition, 2008). Political policies in the United States and in Canada have continually focused on dehospitalization to minimize the increased medical expenses (Glazer, 1993; Ontario Health Coalition, 2008).

Penning, Brackley, and Allan (2006) note that the shift from institutional care (such as hospitals) to community–based services (long term care facilities or homecare) has been the federal and provincial governments’ primary attempt to reduce overall costs in the provision of institutional medical care. Unfortunately, funding cuts have not only been applied to hospitals but also to “long term care facilities, homecare, OHIP and other programs and services.” (Ontario Health Coalition, 2008, p.9). Since the 1990’s, caregivers, in the Canadian context, have been impacted by “who receives services, what services are available and the extent of services available” (Penning, Brackley & Allan, 2006, p. 746).

As a white, female social worker who has worked in a chronic care hospital for a number of years, I have become particularly interested in the experiences of women caring for their male spouse who became ill; their experiences of caregiving in the home but also their experiences when they have to place their spouse in a long term care facility. Many older female spouses have shared their stories with me and, consequently, their concerns related to the impacts on them and on their spouse of the cost-cutting health care trend. Once the elderly person does, in fact, have to transfer from either an acute care or chronic care hospital to a long term care facility, they become the ‘new’ resident and, together with their informal caregivers/family member(s), have to explore and negotiate their new environment and place of care.

LITERATURE REVIEW

Milligan (2003) states that as a person shifts places of care from their own home to the public or market space of a hospital or long term care facility, care recipients undergo a change in social location. The care recipient no longer identifies their private home as their main ‘home’ but now has to adjust to calling a public institution ‘home.’ Elderly wives experience great difficulty when their husbands leave their private home because their care needs have become too great for them to manage at home. When their spouse moves into long term care, they experience frustration again. These moves change their role from being the primary caregiver to an informal caregiver. Thus multiple moves are difficult on many levels; not only does the husband leave the family home but the elderly female spouse experiences a shift in roles as well. Many of the elderly women I have worked with express their frustration and anxiety regarding yet one more move to another public institution (that is moving from the hospital to a nursing home). Elderly female spouses then cease to be the main caregiver and become informal caregivers working alongside the professional staff in a long term care facility.

Spitze and Ward identify female spouses as being “well-suited for providing care when one is sick or needs personal help…sick care may continue to be associated more with traditional gender expectations for women than for men’ (2000, p. 452). The concept of females caring for family members when they are sick is affiliated with a caregiver discourse that articulates how it is women who are socially expected to care for their family members, particularly their spouses. In caring for their spouses, elderly females feel they are social beings who are seen as "worthy, independent citizens" (Sinding & Aronson, 2003, p. 99). Elderly female spouses are, in turn, viewed as 'good' wives by doing so. The 'good' wife discourse includes the notion that she is the person most responsible and should be caring for her husband, regardless of the type of care her spouse requires (Sinding & Aronson, 2003). This act of caring for her husband is socially recognized as a positive way of being and one for which she might well receive affirmation (Aronson, 2006). In addition, when the husband moves to a long term care facility, the elderly female spouse is also experiencing a shift in social location, that is, no longer the primary caregiver but informal caregiver.

When the person afflicted with dementia is placed in a long term care facility, family members often feel committed to frequently visit their relatives (Greene & Monahan, 1987). The research literature suggests the relationship between family members and paid formal staff in nursing homes is not well documented or understood (Duncan & Morgan 1994; Hertzberg & Ekman 1996). Staff and family members report a variety of challenges to developing strong working relationships (Robinson et al., 2007). Discrepancies between staff and informal carers appear quite common with regards to "respective roles and approaches to caring for the resident (Nolan & Dellasega, 1999; Butcher, Holkup & Maas, 2001; Bauer & Nay, 2003). The roles and approaches nursing home staff take then, affect the elderly women's perceptions of the caregiving experience upon placing their spouse in a long term care facility. To better understand the experiences and perceptions of elderly female spouses who have placed their husbands in long term care, one needs to look more closely at how person-centred care plays a role within the long term care facility and affects them as informal caregivers.

Hill points out that, despite an increased social awareness of person-centered care within long term care facilities, government policy still focuses on "pathology, funding institutions (and) not enabling residents but managing their deficits" (2008, p. 22). The Ontario Long-Term Care Homes (LTCH) Act speaks to person-centred care, in that it clearly outlines the resident will be assessed and a plan of care determined which is reviewed /revised all by health care experts (Long Term Care Act, 2007). Furthermore the LTCH Act also discusses the resident's (along with their families who often act as substitute decision makers) right to fully participate in his or her plan of care and in making any decisions concerning all aspects of care (2007). The value of reflecting the voice of family members in all aspects of care is a "key concept in federal and provincial documents on mental health promotion" (Townsend, 1998, p. 38). There is tension, however, between the current emphasis on person-centered care in the legislation and the 'top down' expertise approach service providers actually utilize with family members and residents alike in a long term care setting.

Person-centered care discourse includes communicating and acknowledging the resident and their caregiver's ways of knowing in all aspects of care. This model of person-centered or resident-centered care means respect is given to each individual, with the care planned around the resident's needs (Nolan & Dellasega, 1999; Whitbread, 2006). Hill (2008) includes the following aspects under the notion of person-centered care for those with dementia (within a nursing home): understanding the disease, a care plan that is focused on all of the client’s needs and not just on the practical tasks, staff who stay focused on the remaining abilities and skills of the client and, lastly, the integration of activity programs into overall care which are satisfying for both the client and family (2008). Hill goes on to say that, in fact, person-centered care does not manifest itself, rather practical nursing care or task-centeredness, as determined by the organization, continues to be the focus while families are perceived as being in the way (2008). As a result, the patient’s or the family’s way of knowing is often not heard, nor is their way often captured in the patient’s daily care plans. Consequently, elderly wives may be left wondering how they ought to be both *caring for* - that is, in a practical sense, providing support or labour - and *caring about* - demonstrating affection, concern and love - for their spouse (Finley, Roberts & Banahan, 1988; Guberman, Maheu & Maille 1992). I would also add *caring with* a spouse, with the emphasis here on the reciprocity of the marital relationship; the spouses caring for one another (Graham & Bassett, 2006). I will discuss all three of these concepts of *caring for, about* and *with* separately in the paragraphs to follow.

Trying to understand the complexity of understanding what *caring for* looks like, who does what and most importantly, how female spouses do not always fit into this notion of *caring for* once their husband is placed, remains a challenge. Much of the literature has focused on the staff’s provision of practical care for the resident and on the family’s participation in the provision of care (Duncan & Morgan, 1994; Kellet, 2000; Gladstone & Wexler, 2000, Robinson et al. 2007). Duncan and Morgan note that, because of basic social structures, family can best manage “unpredictable events and nonuniform tasks with many contingencies, (and) by contrast formal organizations can best manage knowledge and expertise…the key variable is the amount of technical knowledge required”: that is, families, in particular, may well be suited for caregiving tasks (1994, p. 235). Schwartz and Vogel (1990) state that personal care and the activities the resident is involved in remains the responsibility of the staff, even though families may want to share in providing those tasks. In comparison, Bowers (1988) found caregivers did not, in fact, view their experiences in terms of what tasks they ought to be involved with or not, rather they viewed their contribution as a way of minimizing the sense of burden or nuisance their relative might be to the staff.

Burden related to caregiving, as defined by Miller and McFall (1992), is a multi-dimensional concept which they break down into 2 categories; personal burden and interpersonal burden. Personal burden, according to these authors, refers to the caregiver’s “appraisal of limitations in personal actions and activities because of providing care” and interpersonal burden represents “the caregiver’s appraisal of problematic behaviours of the older person” who lives in a long term care facility (1992, p.379). Caregivers then are concerned that their spouse is a burden to nursing home staff. Caregiving as a burden, to the female spouse is tied into their role in *caring for* and *about*, now that their spouse has been placed. There is a link then, between the perceptions’ caregivers have, as informal caregivers, of the quality of care staff provide in the institutional setting, and the amount of strain or anxiousness they experience (Pratt, Schmall, Wright & Hare, 1987). There are tendencies for an elderly female caregiver to withhold information lest there be negative repercussions from the nursing home staff toward their spouse (Astedt-Kurki, Paunonen & Lehti, 1997; Kellet, 2000). Therefore, caregivers, in *caring for* their husbands, can be left feeling exhausted and worried their spouse will not receive the kind of personal care they believe they need and deserve as they may not share their concerns with staff.

Traditional, western, normative marital discourse also includes the understanding or expectations that elderly spouses will feel a sense of obligation/responsibility, duty and self sacrifice, which is then reflected in how they care for their spouses, who are no longer capable of doing this for themselves (Finley et. al, 1988; Pratt, Schmall & Wright, 1987). In other words, women are expected to express their care for their spouse in a practical sense and because they do not want their spouse to be perceived as a burden for anyone. As the above literature suggests, for elderly female caregivers, their ability to provide care for their spouse residing in a nursing home may change as compared to when their spouses were still residing in their marital home, as nursing staff are now actively involved in providing personal care. For these women, the focus on the type of caregiving they provide to their spouse shifts to a lesser degree of *caring for* and more towards *caring about* their elderly spouse (that is, showing love and affection). I will continue to address the notion of *caring for* and *about* in greater detail in the following paragraphs.

When an elderly male spouse moves into a long term care facility, one needs to look more closely at how he is *cared for* and *about* by the elderly wife. The feminine ethic of care, as Chodorow (1978) outlines, refers to the socialization process of women who are socially defined as mothers and are the primary nurturer of their child. This nurturing or caring role is then carried over to other relationships, "in which women define and redefine their identity in relation to a set of nurturing roles" (Freedberg, 1993, p. 535). Nurturing is a way that women *care for* - assisting with practical tasks and *about* - showing love and affection. The *caring for* and *about* roles women have taken on throughout history manifests themselves not only in the relationship they have with their children, but also with their elderly spouses (Noddings, 2001). A feminist perspective on caregiving is certainly well documented in the literature (Equal Opportunities Commission, 1982; Gilligan, 1982, Guberman et. al, 1992, Ungerson, 1983). Reverby (1987) suggests women cannot escape the social expectation that they ought to provide direct care and includes showing love and affection.

The degree of affection that is present between the caregiver spouse and the care-recipient in a long term care setting, suggests that it is dependent upon the emotional ties previously established (Finley et. al. 1988; Guberman et al. 1992). These authors go on to say that love and affection shown previously within the relationship can be a motivator to continue caring about their relative or an attitude of filial obligation toward aging parents and, I would suggest, an elderly spouse (Finley et. al, 1988).

The second aspect - *caring about* one's spouse - becomes more complex once the frail elderly spouse has been placed in an institution such as a hospital or nursing home. The love and affection shown to a spouse in the martial home tends to change once their relative is placed within a public building. Given that long term facilities and hospitals alike now provide the practical *care for* their relative, spouses often focus their *caring about,* demonstrations of their love and affection for their spouse, during their visits with them or socializing with them during recreational activities (Wright, 2000). As caregivers visit regularly with their spouses, they may bring in more personal items like clothing/pictures, provide companionship, and focus less on providing personal *care for* their spouse (Wright, 2000). The literature emphasizes the customary visits spouses make, noting these visits can be up to 5 times a week (Willcocks, Peace & Kellaher, 1987; Schwartz & Vogel, 1990). This "extra" care of visiting and socializing with one's spouse is care that is "generally provided out of affection and family obligation" (Sanderson & Meyers, 2003). Thus, if elderly spouses do visit and show affection, the authors above are suggesting it is mainly due to their commitment to their marriage.

As elderly spouses visit with their cognitively impaired spouses in the nursing home and observe physical/cognitive changes, so too may their views on how they express love and affection change. Gladstone (1995) states many spouses, who have placed their husbands in a nursing home, note a tremendous loss of companionship and, therefore, in a sense feel the marriage has ended. Andershed (2006) argues that as the emotional ties lessen between the spouse with dementia and the cognitively-intact spouse, the self-identity of both begins to change. If elderly women perceive a lack of social responses from their husbands, it may mean they respond to them with anger, guilt and sadness (Cohen et al., 1985). Thus, elderly women may, in fact, struggle with how to show love and affection towards their spouse in the ever changing notion of marriage.

While I was able to access some research literature on *caring for* and *caring about*, there was a paucity of research addressing the notion of *caring with* in this context. *Caring with* highlights the reciprocity of caring that can occur between husband

and wife. If care recipients diagnosed with Alzheimer's disease have limited cognitive functioning, the lack of intimacy apparent in conversation affects the quality of the marital relationship even more (Gwyther, 1990). Thus an elderly female's ability to *care with* her cognitively impaired spouse becomes more challenging, as her husband's ability to participate in meaningful conversations diminishes. Wright (1991) also found that caregivers whose spouses had an Alzheimer's diagnosis experienced losses with regards to shared meaning between spouses, which included such characteristics of marriage as expression of tension, sexuality and complete marital quality. As the cognitively impaired spouse declines in health, he is no longer able to reciprocate mutual feelings and have meaningful conversations, which would signify a loss of positive qualities once inherent in the married relationship. Hayes, Boylstein, & Zimmerman (2009) also indicate that spouses of residents who have dementia reported "diminished intimacy" as a result of the disease and wives, in particular, detailed that "changes in their spouse's identity altered how they identified themselves within the marriage" (p. 48). Self – identity is formed through attitudes, beliefs and ideas that are fashioned or maintained through social interactions (Berger, 1966). Intimacy then is linked to consensual worth of reciprocal expression of feelings of trust and emotional closeness (Jourard, 1971). Therefore, elderly female spouses may feel less connected to their cognitively impaired spouse and this, in turn, marks a shift in how they view their identity within the marriage.

Other studies, such as Graham & Bassett's (2006) article point out that caregiving is largely documented from the perspective of the well spouse rather than from "a compassionate act of shared relationship" (p. 335). Their findings put forward the notion of give-and-take within the marital relationship, which appears richer and more ambiguous than commonly perceived, and suggest that despite the resident's cognitive impairments shared meanings can still be experienced (p. 335). While the above authors have begun to address reciprocity between a care-recipient and their spouse, there is clearly still more research needed in this area.

Critique of Existing Research

As Hey points out "the existing accounts (of care giving) tend to take the form of superficial 'customer satisfaction' surveys and hence lack the 'thick descriptions' that can offer important insights into the social process of ageing" (1999, p. 96). I would concur with Hey as much of the literature (see, Hertzberg & Ekman, 2000; Spitze & Ward, 2000; Ashley & Kleinpeter, 2002; Robinson et al., 2007) use mainly quantitative research in discussing the caregiver's experience. They also present their research methodologically from a positivist perspective; that is, they are concerned with seeking "to verify causality and attempt to sort out what really causes what" (Rubin & Babbie, 2001, p. 34). The emphasis then is on the professional experts or the social/health scientists' interpretation of the caregiver's experience rather than allowing them to share their knowledge and inform us. For example, research conducted by VON (Victorian Order of Nurses) on caregivers providing care for their relative, in the community, stated several risk factors these caregivers may encounter which could lead to a breakdown of caregiving in the home, and, I would add, the need then for an alternate level of care such as a nursing home (www.von.ca/en/caregiving/docs/VONCaregiversRiskFactorsReportFinal.pdf). It is interesting to note this report was written by professional experts, such as nurses and social workers, as they were the ones deemed 'credible' to inform other professionals as well as policy makers (Human Resources & Skills Development Canada, 2008). One is made keenly aware that this positivist report did not interview caregivers directly as their knowledge was not considered as valuable as that of the professionals.

While some of the literature reports on qualitative research studies, many of these are also problematic. For example, Kellett, (2000) and Wright's (2000) articles do address caregiving issues utilizing qualitative methods and interpretative methodology; that is, "to understand and describe meaningful social action" (Neuman, 1997 p. 83). However, the researchers still present themselves as neutral authors and the data in an expert manner consistent with positivism (Neuman, 1997). In Wright's article she also individualizes the problem and anticipates nursing staff will find solutions together with caregivers to address such issues as; checking the quality of care, visiting regularly, providing personal care, and handling the resident's finances (2000). While the articles written by both Kellett and Wright begin to highlight caregiver's perspectives and experiences, they do not critically speak to notions of power, gender, the economy or the state. Similarly, Gladstone & Wexler (2000) used qualitative methods and interpretative methodology, thus drawing attention to individual caregiver's experiences in relation to the long term care staff in the Hamilton, Ontario area. My concern with this article is two-fold. Firstly, the data collected did not allow the caregiver to tell their own story, rather it focused on the interaction between them and staff and, secondly, the issues raised were not interpreted through a critical lens. A critical researcher or perspective notes that one's social reality is "historical realism in which reality is seen as constantly shaped by social, political and cultural factors" (Neuman, 1997, p. 75).

In addition, researchers Robinson et al., (2007) also interviewed elderly female caregivers, but did so in the presence of staff which can constrain what the caregiver may or may not say. In research studies in which caregivers are interviewed without staff present, researchers have neglected to state their own social location and the impact this would have on their study (Hertzberg & Ekman; 2000, Duncan & Morgan; 1994).

Research Question

Given that the elderly female caregiver's voice often goes unheard, as noted in the literature review above; I believe it is important to capture the everyday experiences of caregivers. Hence, this thesis reports on my research into the following research question: As elderly female caregivers are separated from their spouses' with Alzheimer's disease, who have been placed in a long term care facility, and must navigate through this unexpected life stage, what experiences do they have in *caring for, about* and *with* their spouse now living in a long term care facility? In essence, I believe these women are charting a course and learning things from which others may benefit and from which service providers can learn. In exploring their perspective on providing care for their spouse, it was my intent to give voice to a small group of elderly female caregivers in the Hamilton community.

METHODS AND METHODOLOGY

Introduction

For the purposes of this thesis, I utilized qualitative research methods to explore the experiences of elderly female caregivers who had placed their husbands in a long term care facility. Qualitative data allows the social researcher to gain detailed knowledge and understanding “through participant observation, direct observation… (and) interviewing” (Rubin & Babbie, 2001). I also chose to approach my research from an interpretive standpoint as it reinforces the notion that “social beings …create meaning and constantly (try to) make sense of their worlds” (Neuman, 1997, p. 83). By utilizing an interpretative approach, one can begin to understand the meaningful everyday lived experiences or social reality of the participants (Neuman, 1997). Furthermore, I have incorporated a critical perspective which reveals a social reality that is “conflict filled and governed by hidden underlying structures” (Neuman, 1997, p. 83). A critical perspective in essence tries to reveal that one’s social reality has multiple layers that are steeped in structures (Neuman, 1997). Neuman goes on to say that by highlighting the underlying structures, individuals can begin to be empowered to change their social reality.

I also included modified grounded theory, which interprets data by collating and comparing similar patterns or categories as a way of further understanding my findings (Charmaz, 2006). Given my interest in recognizing how social beings make and create meaning, I have interpreted the data from an institutional ethnographic viewpoint as well. Institutional ethnography implies that social relations are interwoven with one another and people are therefore linked to "power, knowledge, capitalism, patriarchy, race, economy and (the) state (Campbell, 2002, p. 27). In addition, I explored institutional ethnography to understand the relationships that occur between the organization (hospitals and long term care facilities) and the professionals who work there and family members.

Data Collection

In critiquing the above articles, I found that the content lacked both the first hand experiences of elderly female caregivers and the critical analysis of such. For my research project I have, therefore, chosen to explore their stories as they navigate through this unanticipated stage of life and separation from their spouse. With the permission of all participants (see Appendix A Letter of Information/Consent), each single interview session was approximately 1-2 hours in length and followed a semi-structured interview guide (see Appendix B). Interviews with each participant were either held in their home or in a mutually agreed upon community setting. Each qualitative interview was audio taped and hand written notes were taken. The audio tapes were then professionally transcribed (transcriptions ranged between 15-22 pages each) and analyzed for content. After each interview was completed, each participant received information entitled Help Sheet (see Appendix C) which detailed a list of community resources that they could contact if they felt the need to further discuss their caregiving experience.

Data Analysis

I utilized a constant comparative method (Glazer and Strauss, 1967) to compare data with data, that is, to find similarities and differences. The process of comparing data and identifying categories allowed me, as the researcher, to make analytic sense of “taken-for-granted understandings” (Charmaz, 2006, p.54). As a feminist researcher I chose to look at the data collected, as mentioned above, from a critical and interpretative perspective. By interpreting the data from an institutional ethnography perspective one can critically, “provide a point of entry for understanding” for elderly female caregiver’s “experiences and accounts” in caring for their spouse who has been placed in a nursing home (Aronson, 2006, p. 539). Including ethnography as a way of understanding the societal roles and identities of caregiver’s will indeed give the reader a ‘bird’s eye view’ into their experience. Or, as Sinding and Aronson point out, the interviews will likely expose “disparities between people’s experiences and the cultural prescription and images related to those experiences” (2003, p. 115).

It was my hope that the research would reveal social conditions and caregiver’s experiences as “creative, adaptive people with unrealized potential” in a social reality that is conflict ridden and “governed by hidden underlying structures” (Neuman, 1997, p. 83). I anticipated the research would further reveal the relationship between the caregiver’s experience and their spouse interweaves with notions of power, gender, class, the economy, the state and culture in an intricate and complex way.

My Social Location

My own social location within this research project also needs to be identified. I am a white, female, middle class social worker, currently employed at a chronic care hospital in the Hamilton area. My position as a social worker is naturally accompanied by professional discursive power. As social workers interact with clients, DeMontigny

(1995) suggests they use their "ideological practice to produce specialized professional discourse (that is assessing and documenting based on particular theories and classifications of symptoms) for managing and coordinating work amongst themselves and other organizational professionals and for connecting their work to that of psychologists, psychiatrists, nurses…occupational therapists (p.64). By classifying a caregiver with stress symptoms, for example, or grieving issues, the social worker has also established a "a social relation of dominance and subordination" in relation to the family member (Campbell & Gregor, 2002, p.22). In addition de Montigny states that documents have the capacity "to appear as impersonal and objective (which) makes them extremely effective conveyors of professional power and authority" (1995, p. 64).

It is important to note that my position may in and of itself limit the elderly female caregivers to express themselves freely. They may be leery of social workers (depending their past experience with them), or they may tend to communicate rather easily with me the researcher as I am not directly linked to the nursing home their spouse resides in, and/or they have had relatively pleasant experiences with long term care facility's social workers.

Potential Advantages and Risks of My Social Location

LaSala addresses the importance of researchers identifying themselves as an insider or as an outsider, or possibly both (2003). He also points out there are both advantages and limitations to being an insider (2003). Clearly, I am an insider as I conduct this research, as I have worked with patients in a chronic care hospital, who have been diagnosed with complex chronic diseases (such as dementia, MS, diabetes, end stage lung disease and cancer) and their caregivers. I have had the privilege of counseling many caregivers over the past 6 years, in a both an acute and chronic care hospital. Their stories have included issues related to grief, loneliness and financial challenges. In this sense, I am aware of what caregivers identify as their concerns in the hospital setting. In the chronic care hospital setting for example, I have worked with caregivers, who had already placed their spouse in a long term care facility, and needed the hospital's specialized dementia unit for a time to assist the patient with managing verbally or physically aggressive behaviours. Another advantage I have as a researcher is my knowledge of dementia, patient care associated with their spouse, and the future challenges the patient will face due to this disease.

At the same time, my professional knowledge might represent a limitation. LaSala (2003) advises researchers to be mindful of that which may seem familiar and to adequately explore common cultural phenomena (such as comments that might be made about aging). My work with elderly female caregivers necessitates being cognizant of caregiver discourse and comments regarding the aging process while hearing the participants' caregiving experiences. Upon hearing the experiences of the caregivers I chose to remain fairly quiet during the interview, so as not to verbalize caregiver discourse or speak to the aging process. I reminded myself in hearing the caregiver's stories that I was there in the capacity of a researcher and did not need to use my social work assessment skills during the interview.

In addition to being an insider, I am also an outsider with regards to this research project. I am not elderly myself nor have I cared for someone who is. Given my younger age, the interviewee may well think of me as close in age with their granddaughter or even perhaps daughter. My age and lack of direct caregiving experience may also inadvertently influence the nature of the information shared during the interview process. The age difference "intensifies the inherent difficulties of understanding the 'other' in research (as in life) and the delicate interpretative manoeuvres involved in meaning-making (and thus of sustaining an interaction) are common" as Hey says "to all interview exchanges" (1999, p. 108).

Potential Advantages and Risks of My Research Methodology

In Sinding and Aronson's article, they discuss the element of risk when interviewing research participants (2003). They go on to say that participants may be vulnerable during the course of the interview as they and researchers are surrounded by discourse, such as "the good caregiver" or, I would add, the 'good wife' in light of the political context of diminished health care services (2003, p. 101). The comments are consistent with critically analyzing social reality "governed by hidden underlying structures" (Neuman. 1997). This article also highlights how 'good caregiver' discourse could expose "participant failures" or feelings of guilt. (Sinding & Aronson, 2003, p.101). As Sinding points out, it is very tempting to take up the discourse and respond to the participants by telling them they will be alright. During the interview I will need, once again, to be cognizant of how easily it can be to, in fact, to take up the 'good caregiver/wife' discourse with relative ease, given my professional social work training which encourages one to affirm the client's ability to care for their family member.

Grief discourse is also interwoven in to the dialogue between a researcher and the participant. In Sanders, Marwit, Meuser and Harrington’s article, the authors’ state little attention has been paid to individuals with end stage dementia and, consequently, caregivers’ needs, particularly in terms of grief (2007). Foote and Frank identify grief discourse as social meanings or concepts affiliated with grief and being both ‘normal’ and ‘abnormal’ which is imbedded in medical ideology (1999). Normal grief refers to a “socially approved means of expressing emotion associated with grief” (Brabant, 2002). Abnormal grief then is grief which lasts longer or is prolonged and therefore viewed as problematic or complicated grief (Rando, 1993). Furthermore, Foote and Frank note professionals who provide grief counseling are constantly assessing what is normal and what is complicated grief. Sinding and Aronson (2003) argue that interviewers also take up grief discourse in the process of doing research, by gauging the responses of the participants as ‘normal’ or ‘abnormal’ and by taking up these dominant grief concepts. Given my professional experience in grief counseling, it could be quite natural to respond to the participants in a way that reflects grief discourse. During the interview process my professional stance may well align with Hey’s experience - “ my interview approach at times consisted of my own resistance to their answers as well as embracing counseling or caring rather than a ‘pure’ interviewer role” (1999, p. 105). Although I believe a ‘pure’ interview is not possible, as we all have our own bias and subjective viewpoints. Even the nodding of my head during the interview could be interpreted by participants that I am, in fact, taking up both grief and good caregiver/good wife discourse. In their article, Sinding and Aronson go on to say, “social rules that insist grief be hidden” could quite possibly be apparent during the interview and further questions may be needed to reveal a caregiver regrets or failures (2003, p. 114). Given the participants might well have experienced psychological risks such as feeling embarrassed, worried or upset, I provided, as noted in the above paragraphs, an information Help Sheet (see Appendix C) containing a list of contacts for the caregivers to access.

Recruitment

For the purposes of this thesis I contacted the social worker or resident advisor of 3 long term care facilities in the Hamilton area. A recruitment poster detailing the purpose of the study, information regarding the interview process, a sample list of questions, the number of participants required, (3-5 in total) and my contact information was emailed to each of the resident advisors/social workers. They in turn posted the flyer on a bulletin board inside the facility.

I received five phone calls from potential participants for the study. The first elderly female caregiver who contacted me, while initially quite eager to participate in the study, revealed during the phone conversation that she would like to withdraw from the study. Although this participant chose to withdraw, the issues she briefly discussed during the phone conversation reflected similar themes (emotional hardship since the resident's mental/ health decline and fear of complaining regarding personal care the resident receives) raised by the other participants. Four other participants contacted me and stated they were interested in the study. Given four participants were willing to participate in this study, I did not need to contact the VON (Victorian Order of Nursing) caregiver support services to solicit additional participants.

Descriptive Details Regarding the Participants

The participants for this study were four elderly females, who on average were 73 years old. Three of the women I interviewed were Caucasian and one was a woman of colour. All four women had low to middle class income status and had placed their husbands in a long term care facility approximately 3-4 years ago. Prior to admitting their husbands into a long term care facility, these wives cared for their husbands at home ranging from 2-15 years. While still living at home two of the participants' spouses received 2 hours a week for assistance with personal care/housekeeping services from the Community Care Access Center (CCAC). One participant also made use of an adult day program in the community for several hours a week. Their husbands' dominant diagnosis was either Alzheimer's disease or cardiovascular dementia caused by multiple strokes, in addition to a variety of other chronic health conditions or diseases such as heart, diabetes, blindness, deafness and thyroid.

Limitations

In interviewing only four participants, one cannot make generalized statements or assumptions regarding this population. At the same time however, these four interviews provided a wealth of data and will begin to provide a partial understanding into the lives and experiences of elderly female caregivers. Further research is certainly needed to explore and ensure a deeper appreciation of the experiences of elderly female caregivers. It should also be noted these elderly wives were, indeed, very eager to participate in and support the study.

The Interview Process

In interviewing the elderly female caregivers, I asked several questions regarding the caregiving experience. What is it like for you to *care for* your spouse in a practical sense (i.e. feeding and dressing)? How would you describe your sense of financial (if any) and emotional burden as a result of placing your husband in a long term care facility? How do you *care about* your spouse, in terms of showing love and affection? How does your spouse show *caring with* you, or said differently how is reciprocity shown within the relationship? As I interviewed each of the participants, I found that each one of them had so much to say regarding all the questions noted above. Therefore I have addressed each question as a separate chapter. Within the first chapter, I have incorporated the participant's comments on when their spouse first became ill, how they came to the decision to place their husband in a long term care facility and their interactions with staff at the long term care facility. I also included the notion of person centred care within the long term care facility, visiting regularly to care for their spouse, expressions of caregiver burden and financial concerns, and lastly the impact on participants as a result of the cost cutting trend for medical expenses in Ontario. The second chapter embraces the participants' ways of showing love and affection towards their husbands and the ongoing perceptions of the marital relationship. I also discussed how one participant's culture greatly influenced her perception of marital roles and views on showing affection. The third chapter includes the notion of give-and-take within a marriage and how this has changed for participants given their husbands' diagnoses. I also discussed how the participants view their marital identity and continually reconstruct this identity and their views on sexual intimacy based on their husbands' continued physical and mental decline. In the findings and discussion section, I have analyzed the literature and utilized the participant’s quotes. Finally I have added a conclusion/reflection section and ideas for future research.

FINDINGS

Chapter 1: Caring For

The Early Days

As I began each interview, I felt it was necessary to ask each participant to describe in detail when they first noticed physical and mental changes in their spouse and how this then led to hospitalization or a meeting with staff from the Community Care Assess Center to make a decision to place their husband in a nursing home. I chose to do this in order to hear how their story began to unfold and also to better understand how the participants currently *care for* their spouse. The elderly wives noted *caring for* their husbands in their own home anywhere from 2 to 15 years prior to placing them in a long term care facility. They all stated that as their husband’s dementia progressed, symptoms such as increased memory loss, difficulty with everyday functions (such as driving and returning home on their own) became gradually more noticeable. Two out of the four participants utilized nursing and personal support services (assistance with bathing, washing and dressing) for their husbands and household maintenance (cleaning) from the Community Care Access Center (CCAC) while their spouses were still living in the community. These elderly wives collectively described their roles in *caring for* their husbands in terms of personal care, including bathing, dressing, providing medications and transporting them to appointments in the community. The need to handle financial matters and running errands also became more evident. One elderly woman commented;

> He’d be walking down the street, and he would be putting the cane in the air. And, he’d tell me, he went 6 times (down the street) but he didn’t. He may have

> gone twice. So, everything became push, push, push! And he was on a whole slew of medication, 13 pills at breakfast, and every breakfast morning I'd be arguing with him, take the pills (insert name)! His eye sight was so bad he couldn't see where the pills were, and (then) it got to the CCAC stage. And the sleep apnea...he quit breathing 37 times through the night!

Another participant stated:

> Well, of course, you had to help him dress! You had to do that! And then with his fall you see, with him not being able to do anything with (that) hip...when he was walking he was all out on one side, he wasn't straight. So, it meant one leg was shorter than other. So, he had to have his shoe built up on one side. Big shoes! So, he needed help really getting those on. And then he also needed help, he had swelling in his legs. He was on, he's on the water pill of course, but he needed the elastic stockings on. It was wearying, absolutely wearying!

Yet a third participant commented:

> Because when you have a person at home that has a stroke and has brain damage, you have to watch them all the time because you just never ever know what they're going to do!

One can see from the comments these elderly wives have made, that the care they provided at home was physically taxing for them and difficult given on average they were 73 years old. These elderly women in describing the incredible amount of physical assistance they provided for their husbands also noted the difficulties it posed for them. For instance they noted that they could not keep up with their husband's daily physical care because of their own frail bodies and given that a Community Care Assess Center (CCAC) support worker only came to their home once a week. One woman noted how her own mental and physical health declined rapidly shortly after her husband was diagnosed with a stroke. She said this:

> We were in the process of selling the house, everything was packed, his boxes, my boxes, everything was ready to go and he suffered another stroke! So, again,

> he was in a coma and at this point they (hospital staff) said he had a massive stroke, not only in the brain but in the brain stem. So, he now has injury on top of injury! And they said, "he's much worse". By this point in time, my health started to deteriorate. I had already had an experience with my heart where I had spent time in Intensive Care and they worked really hard to keep me alive! And I said, "I can't take care of him!"

The other three participants did not mention any specific health problems, however they did note that they were overall weaker than they used to be and physically not strong enough to sustain physical care for their husbands. It is important to reiterate that the literature states that when a male spouse becomes sick, it is typically the wife who becomes the built-in nurse and caretaker; a caretaker whose proximity and motivations are particularly advantageous in supplying sick care (Litwak, 1985). Traditional gender expectations for women continue to be associated with sick care while living at home (Spitze & Ward, 2000). In addition Ashley and Kleinpeter (2002) state "caring for a demented adult involves physical, social and emotional demands" which results in "adverse physical and mental consequences for the caregiver (p. 33). There is an important implication here for social work practice as well. Social workers need to be reminded of the very physical tasks these elderly female participants engaged in prior to placing their husbands in a nursing home and how fatiguing this process has been for them. There is an implication here for social workers working in the community and in hospitals to be cognizant of how elderly females, who typically are the caregivers, provide heavy physical care for their husbands which in turn can result in mental, emotional and physical consequences for them. If social workers fail to acknowledge the stressors elderly female caregivers may have, they may in fact be at great risk of being hospitalized themselves due to their own health problems.

The Placement Process

Two participant's husbands suffered a series of strokes and, as a result, were admitted to acute care hospital and then discharged to a nursing home relatively quickly. In these two instances the husbands were placed in long term care after having required hospitalization. From the perspective of one elderly wife, the hospital staff indicated to her that due to her husband's multiple strokes, wandering and verbally aggressive behaviour, she should place him in a nursing home. The other older spouse was also told by hospital staff that due to her husband's verbal aggression and increased memory loss, she should consider placing him a nursing home. This second elderly woman shared the following:

> He went into the hospital that morning, he couldn't hold his cup of coffee, the cup was falling so I called the daughter and she said, I'm coming, so, we took him to the hospital. He had all the tests done, because he has a heart condition so the possibility of a stroke. He was at the hospital for one day and they moved him to (name of a long term care facility inserted).

Each of these two participants consented to placing their husband in a long term care facility. Both elderly women mentioned the decision to move their husband to a long term care facility from the hospital as if the hospital made the decision. They certainly did not state this was their idea to place their husband in a long term care facility. One elderly woman expressed relief as her husband's care needs far exceeded what she could provide and consequently her own health was suffering greatly. The other women did not express any feelings regarding this decision; however this could be due to her culture as one does not express feelings openly within her culture. The quick discharge plan or in a sense pushing the patients out to a lower level of care such as a long term care facility speaks to an ongoing health care trend in Canada. Political policies in Ontario continue to be influenced by the restructuring and the privatization of public health care which began in the mid 1990's (Brodie, 2006). As a result of these policies, there was a heightened focus on minimizing the increased medical expenses in acute care settings and offloading the costs to community providers (Aronson & Neysmith, 1996). The Ontario Health Coalition (2008) states that the lack of provincial funding continues to plague hospitals and the constant pressure to reduce or eliminate their deficits largely affect the needs of an aging population. Hospitals are reporting "high numbers of 'Alternate Level of Care' patients...who are considered by hospital executives to require a different level of care than hospital care (for example long term care facility)" (Ontario Health Coalition, 2008, p. 3).

The other two wives were approached by a CCAC representative and asked to consider placing their husbands in a nursing home, due to the increased care the spouse was providing and to the fact that their husbands could no longer be left at home alone for safety reasons. These two participants agreed to place their spouse in a nursing home as well. Neither of these elderly women stated that there was a lack of services provided by CCAC in their home (which ranged from 1-2 hours/weekly), rather they only commented on being, themselves, housebound as a direct result of having to *care for* their spouses and on the increase in personal care needs which they, as elderly women, could no longer provide. The other two participants were not receiving any homecare at all. One participant stated:

> As I say, if I had the facilities, I would prefer to have him home! But then, if I have him at home, then what's going to happen to me? Cause I don't have anyone, right. If I need to just go to the grocery, I need to go somewhere, who is going to keep an eye on him?

The other elderly wife stated that a CCAC representative, who initiated the discussion to place her husband in a nursing home, said to her husband:

> "You know (insert husband's name), your wife can hardly look after you anymore." "Oh (said her husband), she is doing a fine job." He had no idea what I was doing for him!

This participant, along with the other participants who placed their husbands from their home had mixed reactions to this discussion. This elderly woman recognized it was becoming impossible for her to *care for* her husband at home and was relieved that the CCAC support worker was helping her place her husband. One of the participants felt pushed into placing her husband in a nursing home and felt she had no other choice but to do so given her own frail body and lack of social supports. In addition, none of the husbands of the participants had any idea how much care their wives were in fact providing for them.

The statements in the above quotations exemplify the limited social support these elderly female women have in being able to *care for* their spouses in their home. One of the participants stated that she had help from her daughter occasionally, while the other three did not receive any assistance from their children. In addition, none of the participants reported receiving any help from their neighbours. Stoller and Pugleisi

(1991) state that married persons have a smaller network of helpers and that female spouses are at the top of the hierarchy for providing required assistance. Not only were the network of family and friends limited, the support provided through community services remained minimal as well, therefore, placing their loved one in long term care became the only option for all of the participants.

In terms of neo-liberal ideology, the state shifts the responsibility to the individual citizen, in this case the female elderly wife, to provide medical and personal care for their family members as a means of minimizing government transfer payments made to home care health services in the community. None of the elderly women indicated that they understood that they were being ‘dumped on’ by the government to take up more responsibility to care for their husbands. Instead they simply took on the role of the traditional female nurturer/caregiver. In addition then, home care services as mentioned earlier by the Ontario Health Coalition has been cutting transfer support payments to community providers (2008). Aronson and Neysmith (1996) state it this way; “in these turbulent economic and political (times), home health care in the privacy of old people’s homes (is the direct) implication of cost cutting for those at the point of service delivery” (p. 422). It is interesting to note that these 2 participants did not complain that they had not received more home care services in the home. Perhaps one of the reasons for this relates to the concept of stoicism, or to a sense of being impassive. Stoicism, as a construct, is equated with the notion of fatalism, that is a “perceived lack of control” and consequently “negative adjustment style” to one’s circumstances (Fitzpatrick, 2000, p. 2756). Aronson refers to “stoic noncomplainers” as an identity “for which older women might expect approval in the current political context (2006, p. 548). One elderly woman cited:

> And, like, I didn't have anybody coming in and cleaning your house or getting meals or anything - I did all that myself.

Another participant stated "I would sit down and think of the good times. Right? It could be worse, right? I wouldn't say it is an easy journey 'cause I have to do everything." In terms of a neo-liberal agenda, this kind of mentality, that is taking responsibility for one's own care needs, is exactly what government wants elderly persons to embrace. In practice, social workers need to be cognizant of stoicism as elderly women can very easily take up this discourse and, similarly, social workers can be quick to affirm the roles of 'stoic noncomplainers.'

Social workers need to remember that women themselves are not driving the placement to a nursing home (either from a hospital or through CCAC); rather it is the government's neo-liberal agenda which forces women to place their husbands in a nursing home. Elderly women, as noted by the participants, may not be aware of the government's agenda and how this impacts them, rather they may well just be willing to accept it without question. Social workers need to inform elderly female caregivers who do place their husbands in a long term care facility, of the government's agenda and encourage them (if they so wish) to voice their concerns to not only social workers, but also to long term care administrators, and politically to local governing bodies. Failing to give the elderly a venue to voice their concerns only encourages provincial governments to continue slashing vital health care costs and community support services such those provided by the CCAC. Furthermore if women both individually and collectively do not address the lack of health care funding, provincial governments will continue to assume that their cost cutting measures are efficient and effective, regardless of the actual impact these measures have on medically complex and elderly persons and their caregivers.

The Shift from Home to a Long Term Care Facility

In placing their husbands into a long term care facility, participants were asked to describe the shift in the meaning and practice of *caring for* their husbands at home as compared with *caring for* them in a long term care facility. One elderly female spouse commented:

> Well, there’s absolutely nothing similar! I mean it’s a completely different way of life because, you know, he’ll always say he feels so lonely and, of course, I do too… and I’ll say to him sometimes, I said “well, you know, actually you have more company than I do,” because, you know, he has people coming, staff are in and out there, they’re coming in to change his diaper thing, but he, you know, he can’t see that (due to his Alzheimer’s disease).

This elderly woman clearly states that how she *cared for* her husband at home does not resemble the same care she provides for him now. In essence the practical, physical tasks she did previously, such as dressing him, bathing him and cooking for him no longer exists. Simultaneously, she also describes emotionally how difficult it is for her to be alone at home or to be separated physically from her husband. By placing him in a nursing home, she too has become socially isolated because her days now revolve around daily visits to the nursing home. Furthermore, she comments on her husband’s inability to realize he requires a lot of nursing care, more than she could have provided by herself and through CCAC, for him in their home.

Another elderly spouse noted “But it is still hard to know that the family tie is not there anymore. I wouldn’t say it’s not there but, you know, the distance, you wish that he was back home here.” Again this participant comments on how lonely she feels being at home by herself and physically separated from her husband. This participant like the one above visits her husband daily at the nursing home and therefore comments not only the physical distance, between them or the wearing process of going back and forth to the nursing home, but also the lack of emotional ties with her husband now that he lives in a nursing home. When I asked yet another participant if her husband was aware that he was now living in a nursing home she responded;

> Yeah. He does. But he has stopped talking about moving into a place of his own. He did say to me, within the last 2 weeks “you know, I want out of here” and I said “You’re never coming out of here. I’m sorry; I know you don’t want to hear that, but that happens to be that fact of life!” Because, when you have a person at home that has a stroke, and has brain damage, you have to watch them all the time because you just never ever know what they’re going to do!

The comments above reflect public discourse which suggests that nursing homes or long term care facilities symbolize the definitive loss of autonomy for older adults who have a chronic illness or a disability (Ryvicker, 2009). Given the transition of moving their spouse into a long term care facility, one can see how the cognitively impaired person’s routine changes, but the routine of the elderly female spouse still living in the community changes as well. One participant reported that she must continue to work, as her finances have diminished since she placed her spouse (a concept that I will explore in greater detail under the Finance section). Another elderly woman commented “but he won’t be coming home. It’s utterly impossible. My doctor was saying you should keep up your friendships. It is hard to keep up your own interests, mainly because you're tired, you know." One can ascertain from the participants above how much their lives have changed in *caring for* their husbands who now live in a nursing home, namely the unexpected need to work outside of the home, to sustain an income and the loss of friendships. As these elderly female caregivers shift in *caring for* the spouses at home to a nursing home and endure their own loss of autonomy, they also undergo a shift in their marital identity. I will discuss how a caregiver's identity is reconstructed once they place their husband's in a long term care facility, in Chapter 3, in more detail.

Milligan notes that in today's Euro-American society, the "metaphor of displacement - the person who lacks memory and a coherent self-narrative, and who thereby also lacks a proper 'home'" (2003, p. 465). Placing one's spouse then, Milligan goes on to say, can be viewed as a disruption of the previous connection between the carer and care recipient. This concept is clearly reflected in the statements made by the women above. When their husbands were living at home, these elderly female spouses were the main and formal caregivers. Now that their husbands have been placed in a long term care facility, they have become informal carers and have noted their sense of feeling displaced by their changing role in identity. Their role in *caring for* their husbands no longer revolves around providing nursing care or primarily doing practical tasks such as bathing, dressing and giving them medications. Instead the daily routines for both of the spouses and the relationship in *caring for* their husbands have become shaped by the "ruling" routines, practices and policies of the long term care facility (Campbell & Gregor, 2002). Thus the elderly female wives visit with their husbands and socialize but are not primarily involved in the nursing tasks. Both spouses are no longer in their private home to do as they wish; rather they must succumb to living within an institution which no longer symbolizes 'home.' As the place of care shifts from the private home to the "public or market of residential nursing home, informal care-givers and care recipients experience a sense of dislocation and a loss of control over the caregiving experience… through the loss of power to decide on the division of labour between informal carer and care professionals" (Milligan, 2003, p. 465). Or, as Foucault (1967) notes, within the social processes between any and all long term care staff and the residents and their spouses, the workings of power exist.

Staff/Family Interactions

As these elderly spouses negotiate their roles as informal carers within the long term care facility, workings of "institutionally mandated power" exist and is exercised by professionals working there (de Montiguy, 1995, p. 59). By entering the institution, staff are mandated to provide personal care (bathing, feeding and dressing) and in the process of doing so establish a "social relation of dominance and subordination" in relation to family members (Campbell, 2002, p. 22). One elderly spouse cited:

> Like (name inserted) is getting this physiotherapy 3 times a week upstairs at 11:00am, and after lunch they (nursing staff) put him to bed because they figure he's tired from that, so, I've got that figured out, so, I don't come then. But, lots of times I come and he's in bed. It irritates me! I'm thinking why is he in bed all the time? He doesn't need to be in bed! He's not sick you know what I mean?

The statement above reflects this older woman's frustration with the institution's schedule, which does not meet the needs of her spouse and disrupts her ability to visit him as she pleases. In visiting her husband, this elderly woman is *caring for* her husband. Finding him in bed, angers her and may contribute to her sense of guilt in not being able to *care for* him at home, as she knows in *caring for* him at home he was up most of the day. In addition, she states that she would like to socialize with him in the common areas in the nursing home and finding him in his room makes their limited social time together less meaningful for her. Another participant commented:

> The nurses at (name of long term care facility), if they get in his way, he gets angry. He pushes and pushes and now he puts his hands out, cause other residents used to push him down or out of the way. He pushes and he gets you know frustrated, cause I've been there and I cannot discuss anything with the staff.

There is an implication for social workers to take note of elderly spouses who can be left feeling angry and powerless when they have the right to visit and be with their husbands at anytime. Clearly nursing home professionals maintain dominance and the institution's practices when it comes to each resident's daily routine and there is a need to place a higher importance on both the individual resident's needs as well as the spouses'. In addition, social workers need to recognize a spouse's desire to define and implement the best daily care plan for their husband. The care plan is reviewed once a year and this is an opportunity for elderly wives to help *care for* their husbands in a small way. This is not an easy task as social workers need to be reminded of the strained communication, as the participant above remarked that can be inherent in the staff/family interaction, due to professional power being exercised. Elderly wives may in fact not feel that they are informal carers, as they may not have the confidence to speak during this conference and may well feel in a position of subordination. Social workers need to provide elderly spouses sufficient time to voice their husband's care needs, preferences and dislikes, in order to recognize and value their knowledge.

All of the spouses I spoke with indicated that voicing their concerns is either something they do not engage in or when they do it is extremely hard for them. This again reflects an older generation of 'stoic noncomplainers' (Aronson, 2006). On a daily basis, social workers also need to encourage elderly females to voice their concerns regarding how their spouse is *cared for* in the long term care facility, again to maintain their role as the informal caregiver.

Interacting with Doctors

Elderly females in particular may have difficulty speaking out as Aronson (2006) notes they may not want to offend nursing staff or there may be a fear of consequences when they do complain (Coyle, 1999). Bamberger suggests that older women experience "sexism that permeates the health field from education and research to service delivery. In addition they (older women)...experience both age and sex discrimination. Their inferior status in health care delivery is a product of discrimination and is evidenced by the little number of women physicians" (1985, p.1). Not only are predominantly male physicians providing care in long term care facilities, the opportunity to speak with one is limited. As one participant citied:

> So, I saw the doctor here one day, accidentally, you never know when they're coming, that's annoying too and **he** said I'm going over (husband's name inserted) medication, and see if I can cut off some of these pills. And he did. Now I don't know what he cut off really but he did.

As noted by the elderly woman above, she wants to partake in the role of physically *caring for* her husband by watching exactly what kind of medication he is receiving. Another participant stated:

> “It went back up (his cholesterol level) and since then they (nursing home physician) put him back on cholesterol medication. So, I meant to ask them to sort of monitor him, get him off (the cholesterol medication). So, he’s off the diabetic medication but he’s on a diet. So, I still watch the amount even when he comes home for a visit.

This elderly woman still pays close attention to her husband’s medications and in doing so she too, is maintaining her role in *caring for* him, both in the nursing home and at home. What is interesting to note is that both women do not follow through with checking that their husband’s medication levels were adjusted according to their wishes. In a sense these women are left feeling isolated as they do not know what the physician have actually done with their husband’s medication levels. Given the professional power of the staff and limited sharing of information, it is not uncommon for family members to be left feeling powerless, isolated and disengaged and often in disagreement with staff (Kellet, 2000; Bauer & Nay, 2003; Hill, 2008).

Another participant expressed stoicism with regard to the interactions she had with staff:

> Because a person like that (with Alzheimer’s), they’re a dead weight, because they can’t help themselves in any way. So, I always wait now for staff to come and get him up out of the wheel chair, because I won’t leave him (alone) in the wheel chair. I mean, you can’t expect staff to be there the minute you ring the bell, because they have a lot of people to look after and there’s always bells going you know in different rooms. So, I always stay, because I’m always afraid of him taking a chance and getting out of the wheel chair, because he you know, he still thinks, he’s capable of doing all these things.

This participant’s comments reflects her need to *care for* him in terms of staying with him for safety due to his poor cognition, a role she fulfilled earlier as a formal caregiver and one that she continues to engage in. In *caring for* him, she is also noted a change in her role, as the once formal caregiver who helped him transfer, to an informal caregiver who now waits for staff to assist with transferring him out of the wheelchair. While this participant waits for staff to come however, her husband just becomes one of many residents whose care needs are only met when the staff decide to respond to him. In this sense the resident is merely another ‘case’ and the staff exercise their professional decision making power in terms of who receives care and in what order.

The objectification of an individual, namely the resident, and the subordinate role of female family members, as evidenced in the statements above, is consistent with the biomedical model. This model remains prevalent in nursing homes today and continues to be reflected in social policies. The traditional biomedical model is often referred to as a ‘top down’ approach where physicians and health care experts’ diagnose patients and develop/implement a care plan for them (Hill, 2008). Zimmerman and Dabelko state that “patient and family factors identified as problematic in the United States, such as patient involvement in care decisions and care coordination measures, are deeply rooted in the traditional model of health services delivery; for example little room exists for patient involvement in care decisions within a hierarchical structure that emphasizes physician expertise” (2007, p. 35). As noted in all the quotations above, the physician and the nursing home staff decide what medications are prescribed and when/how care is provided. The elderly wives’ involvement in the daily care plan is minimal and only in response to the existing ruling practices and routines of the nursing home staff. The biomedical model or the expert 'top-down' approach makes it very difficult for these elderly spouses, to *care for* their husbands because the long term care facility does not predominantly provide person-centered care.

Person Centered Care

Person centered care within a long term care facility, as outlined in the literature review, remains a highly contested issue. If one looks closely at the Long Term Care Homes Act (LTCHA, 2007) and its policies, as outlined in the introduction, it is not difficult to ascertain the institutional power the long term care facilities do, in fact, exert over residents and their family members. The policy indicates the facilities surveillance of nearly all aspects of a resident's care and there is minimal reference to how person or resident-care is actually incorporated or evaluated in day-to-day care. Long term care facilities are required to have a yearly 'case' conference for each resident. The terminology utilized in describing the resident's care plan, again, highlights the objectification of an individual and the professional/organizational standpoint and reinforces the hierarchy of scientific medical need (Hill, 2008). That is, expert professional discourse is produced by classifying, determining goals and selecting the best treatment plan. This social process reiterates the need for services to be provided in the long term care facility and legitimizes the position of the representatives of the disciplines who attend this meeting i.e. a nurse manager, social worker, recreational therapist (Campbell, 2002).

While the case conference only occurs once a year, the day-to-day interactions between the staff and family members is at the forefront of the elderly female caregiver's experience as noted by the participants in describing their daily visits. In visiting daily, these elderly spouses are *caring for* their spouses by showing concern for their well-being. By clueing into the type of care they see nursing home staff provides, they are in essence monitoring that their spouse receives respectful care that reflects him as a person not an object. When staff do provide 'care' (in the organizational sense) this refers to routines and prescribed care: residents or family members contributions are not formally recognized or recorded (Hertzberg et al., 2000). One participant told me that she performs all of her husband's personal care. When I asked why she did this, she responded that he is on a locked unit and tends to push staff away if they approach to do his care, so they wait for her to come in and do it. This woman, although of retirement age, still works part-time due to her limited finances which means she has to juggle providing personal care for her husband with work shifts. When asked how she copes with working, visiting her husband and interacting with her children/grandchildren, she simply states "you do what you have to do." Again, she does not want to complain and is rather stoic regarding the matter. Another participant stated:

> Oh no, I don't dress or wash him. If I'm taking him out for a doctor's appointment, I mean, I'll help him on with his jacket. I take the wheel chair cab you know, so, that's very handy and the drivers are very nice, they'll wheel him right up into the doctor's office so that's a big help. I have degenerated discs in my neck.

This second elderly female spouse is very frail which makes it difficult to even take her husband to a doctor's appointment without the assistance of wheel-chair accessible taxi drivers. This elderly woman does not have a choice in taking her husband to medical appointments; the long term care expects family or the substitute decision maker, to take residents to any appointments in the community. She did, however, choose to help her husband with his jacket. Wright notes that providing practical support means a change from providing hands on care, as the second participant above states, and instead means taking on the responsibility of “replacing items such as underwear, clothing and shoes and for purchasing sweet and special foods enjoyed by the cared-for person” (2000, p. 658). All the participants I interviewed continued to *care for* their husbands by bringing clothing for them and favourites snacks such as those from fast food restaurants or culturally appropriate food.

Completing tasks such as taking their spouse to an appointment in the community highlights the contributions these elderly spouses make towards their husband’s personal and health care and yet this work can often go unrecognized and simply expected. Practicing social workers need to be reminded of the medical expectations placed on elderly female wives to assist with personal care or to take their spouses out in the community for appointments/treatments. Their physical frailty or need to work can easily be ignored. In addition, social workers have an opportunity here to assist elderly caregivers/spouses, through one to one sessions, as they transition their cognitively impaired spouse to a long term care facility and subsequently identify any ongoing concerns and issues they may have. Social workers are in a unique position to help facilitate staff/family/resident interactions and advocate around any concern or issues on behalf of family members to other staff, in order to maintain personhood or resident-centered care.

Traditional Female Roles of Caregiving

Aronson and Neysmith note that the "dominant policy discourse on long-term care and associated management practices emphasizes the instrumental, practical aspects of home care worker's labour" and I would add, that of the nursing home staff (1996, p. 62). Long-term care facilities employ staff who are predominantly women and have become the substitute for activities that traditionally have fallen upon female relatives in providing *care for* and *about* aging family members (Abel, 1991; Baines, Evans & Neysmith, 1991; Aronson et. al., 1996). The work staff provide is often simply seen as "just an extension of ordinary domestic labour" which is "afforded little value or status, and is seen as fairly unskilled" (Aronson & Neysmith, 1996). In addition, literature reveals that women's work or the notion of caring for their relatives highlights both political and ideological processes at play in the continued devaluing of physically and emotionally caring work for the elderly (Aronson et. al., 1996; Glazer, 1993; James, 1992; Kaplan Daniels, 1987; Ungerson, 1987). As one participant who has been a caregiver for 18 years and placed her husband 3 years ago remarked; "Yeah. You get fed up being the caregiver! You get tired of it. You get frustrated." This participant clearly stated the numerous years of caregiving have left her feeling exhausted through providing socially expected domestic labour for her husband. Similarly the participants noted that it is predominantly women who provide care in the nursing home and as one participant said "there's always new ones (staff)."

Staff turnover rates in long term care facilities, due to lower job satisfaction and low wages, have also contributed due to poorer standards of care (Castle & Engberg, 2006; Hertzberg et al. 2000; Wright, 2000). Nursing homes report difficulties in recruiting nurses and high annual staff turnover rates for not only registered nurses but also care assistants; health care aids and personal support workers (Wright, 2000). Castle et al. add that lower staffing levels and higher bed size homes are associated with higher nursing staff turnover (2006). I asked one elderly woman if she recognized staff and she remarked she did not recognize staff as they are always “chang(ing) shifts.” She went on to say “So sometimes maybe they’re changed from one side over to (name inserted)’s side, then that’ll be a strange face to me.” Maintaining person centred care when the staff are always changing, continues to be a challenge to these elderly spouses as they do not know their husband’s history, likes or dislikes. This participant did tell me however, how she tries to *care for* her husband by getting to know the staff just a little and relate his preferences such as getting up for social activities. Her statements remind social workers of the difficulty for elderly women who have to cope with a sea of faces each time they come in to visit their husband and their need to establish trust and rapport yet again with someone new. I asked another elderly woman the same question and she commented:

> Oh yeah, there’s lots of changes! There is a core, but then you’ll see lots of different ones and then they don’t know the residents. Like they get a coffee for (husband’s name inserted) but he’s blind, so, they’ve got to make sure he’s got that in his hand and knows it’s hot. You get these new ones, and they don’t know he’s blind. I complained and they put a paper right on the wall, but they’re not reading these things. In fact, if I’m there, I got thinking, “are they just putting it down ‘cause they know I’m here?” “Does this happen if I’m not here?”

This participant is trying to *care for* her husband by ensuring that he receives his coffee in his hand, along with some verbal instructions, due to his impaired vision. Unfortunately she is making an attempt to maintain her husband's person-centered care within a system that does not always provide adequate care. Even though this particular spouse had the courage to speak up regarding one of her husband's needs, she is not convinced that staff follows through with her requests given the constant turnover of staff. This older woman also raises the issue of making regular visits to make sure her husband is receiving the specific care he requires.

Regular Visits and Caregiver Burden

When a family member is placed, family caregivers (as noted above) tend to check on the quality of care by visiting regularly and trying to provide some personal care themselves (Duncan & Morgan, 1994; Wright, 2000). Literature also highlights the habitual visits spouses make, as they can be up to 5 times a week (Willcocks et al., 1987; Schwartz & Vogel, 1990). Three of the participants I interviewed stated they visited everyday or every other day and the fourth participant visited 1-2 times a week. One elderly woman made this comment:

> I don't think I'd like to be somewhere all day alone, and nobody coming so, I pop in and out. And if I don't come the odd time, because I've been busy doing whatever through the day, I'll say to myself, I'll go after supper for 20 minutes or so.

This elderly woman is certainly continuing to *care for* her husband by visiting him daily. She notes how important it is for him to have regular contact with her now that he resides in an institution, a place which she feels one can experience loneliness in.

For the other participants, *caring for* their husbands through regular visits also invokes a sense of guilt. One elderly woman who visits every other day stated; "I think I've spoken with other people too, caregivers, I think the guilt is the worst thing you have to deal with." Another elderly spouse who reflected on the need to visit daily cited:

> More guilt (pause, tears), because I know, he's well looked after here except that you don't know, that he's wandering away from the building (as he has done this before and staff returned him to the facility some time later).

Another older woman told me her daughter says to her "you're feeling guilty; you got to go and see Dad every day. You don't have to worry." Despite the words of wisdom and encouragement from this participant's daughter, this elderly woman still visits daily and takes her husband home 2- 3 times a week for visits.

Wright implies elderly female caregivers visit due to a sense of obligation and a feeling of guilt that the cared-for person now living in a nursing home (2000). Wright continues to state, the feelings of guilt often experienced by a female elderly caregiver can be "fuelled by the role of expectations in our society" (p. 655). Although the quotations noted above by the elderly female participants did not explicitly state that they feel obligated to visit regularly, they did speak to feelings of guilt when they did not visit. These feelings of guilt reflect that they are responding to some kind of social expectation, that is being the 'good wife' or 'good caregiver' who *cares for* her husband, by physically being present through visits and providing him with social stimulation.

As these female elderly women speak to feelings of guilt they simultaneously speak to the notion of burden, a concept that was explored in the introduction. The participants are, once again, surrounded by discourses of the 'good wife' and 'good caregiver.' As

Hertzberg et al. (2000) adds, "traditional family nursing has certain expectations about the behaviour of a 'good' family in a situation where a family member is in long term care," (p. 615). Robinson (1994) also states that traditional nursing views family members as a backcloth rather than part of the nursing process. Thus family members are socially expected to visit but not to interfere with the routine care they as nurses provide. This view is not a holistic one or person centered as it does not recognize the valuable contribution spouses do make in *caring for* their husbands, now living in a nursing home. Since the caregiver's contribution remains largely unrecognized, they can often be left feeling that their family member requires a lot of care and they are therefore a burden to the nursing staff in a long term care facility. The following are statements the elderly female spouses made with regards to feeling a sense of burden:

> You know I wouldn't say I'm happy or unhappy, I'm in between. I don't want anything to happen to me, then I will be a burden to somebody else. He's a burden so you don't want to add another one.

Another elderly wife stated:

> Yeah I usually go about 4 times a week. But I mean…you feel so guilty so if you don't go that's the thing you know. So you just have to cope with that. But even…even though he's been there what 3 years…he still wants to come home. So that's the hardest thing, very, very difficult. So you do feel…you maybe let them down a bit you know. Because the way he put it was well if it was the opposite way around I would look after you.

It should be noted that this woman's husband has Alzheimer's disease and even though he states that he wishes to go home, he does not realize the extent of care he now requires. Even though the care this participant's husband requires, far exceeds what she alone (with limited community supports) could provide for him, she still feels guilty that, she is not physically spending more time with him. Unfortunately seniors who require more health care are considered a burden to the health system. Society continues to value 'life-saving' medical treatments above 'life-enhancing' treatments (Harris, 1987). We also live in a culture which privileges having an able body over having a disabled body (Titchkosky, 2008). Thus older adults who require nursing care are considered a drain to the health care system and are not valued the same as a citizen who is younger, healthier and financially contributing to societal costs. Nevertheless, the emotional impact his words (see quotation above) have on his wife, along with the comments made by the other participants regarding the notion of guilt, is profound and should not go unnoticed by social workers. The research then supports Kellet's (2000) findings, that caregivers do, indeed, live in a constant state of anxiety and can have feelings of helplessness. I believe the participants did express feelings of anxiety and helplessness knowing that they only visit once a day and do not see their family members all the time and largely remain unaware of the type of care they are receiving. The participants also noted how they in a large part feel guilty because they cannot be at the nursing home all the time, as many of their spouses would have liked. Again, this also reiterates the elderly female spouse's sense that their husband is a burden to society because they are in a nursing home and she is not *caring for* him in their own private home. There is an opportunity here for social workers to be attentive to elderly women's expressions of guilt and sense of burden, fuelled by social expectations, when interacting with them both in a long term care facility and in a hospital setting. Social workers also need to be cognizant that while elderly female caregivers cannot *care for* their spouses at home any longer, they continue to *care for* their husbands and maintain personhood in vital ways which include visiting them regularly and interacting with them socially. In addition, social workers may also want to persuade elderly female caregivers, to share their stories with one another, in an effort to gain knowledge from one another.

Finances

In addition to providing personal care, elderly female spouses have to handle the family finances, which is yet another aspect of *caring for* their spouse. All the participants noted how the traditional gender expectations operating in their marriages did not include their having to handle the family finances; this was a new role they had to take on. Wright remarks in her study that wife caregivers can be intimidated by the financial complexities (2000). One older woman stated that since her husband has been in long term care:

> All of a sudden, there’s nobody there and that’s when the loneliness sets in. That’s when the reality of, oh, I have to go pick up the dog food, I have to put the garbage out! I always did watch the finances, but now I had the additional responsibilities with the finances!

This participant notes that she used be careful about how much she spent and her husband’s responsibility was to make sure all of their expenses were paid. She certainly indicated by her tone of voice that this shift in role responsibility has been an unwelcome change and challenging for her. Besides handling the finances, two participants also talked about selling their home and downsizing for financial reasons. Another elderly woman made this comment: “I still would you know think of him if anybody asks, you know, he’s still the head of the family although I do all the decision making.” Even though this elderly woman has taken on the added responsibility of making financial and household decisions, it is still so incongruent with her understanding of her marriage and the roles that traditionally she sees as either the female or male's within a marriage.

In managing the household expenses, spouses were concerned with the large amounts of monies (relative to their income per month) needed for their spouses who are in long term care and the impact this has had on their own lives. My findings are consistent with Pearlin and Aneshensel (1994), who report that caregivers, who place their husbands in a long term care facility, continue to be exposed to stress, depending on "their economic, social and personal resources." Thus, the monies the elderly female spouses have left to live off of in the community are problematic for many of them. One older women, who I mentioned earlier, was forced to continue working as their family savings were beginning to run out due to her husband's early (in his 50's) diagnosis. In order to *care for* her husband, that is for him to remain in the nursing home; she absolutely has to keep working to meet all of their combined financial expenses. Another woman who has been caregiving for 18 years stated:

> I had a job when I was able to work. I had a job that I loved and was friendly with, and social with. When I took ill (in addition to her husband's multiple strokes), it was like starting all over again and having to learn to cope with all emotions. There were many tears, many tears and a lot of frustration, a lot of anger then again, you get to a point of well what am I going to do about it?

This particular participant never returned to work and has been living on minimal income. She told me one of her sons moved in with her and that has helped financially, however her monthly income remains very restricted. This participant is at a great disadvantage because in *caring for* him, it means a portion of her income goes towards keeping him in a care facility. Another quite elderly woman who spoke of being affected financially noted the following:

> Supposing I had to, not necessarily long term care, but say a residence which sometimes I would almost like to be in a residence, to have my meals made, because I find after I visited with (husband's name inserted), by the time I get home…well I'm tired! The thing is, you don't know how long you are going to live. I mean, if you were to say to me, you're going to die in 2 or 3 years, well, I'd go into residence tomorrow. But I mean who knows when you're going to die!

As this elderly woman points out so eloquently, she would indeed like to live in a retirement home and yet, realistically, her finances remain very limited and this is not a feasible option for her in the long term. Once again her finances are going towards her husband's care and this is how she has chosen to *care for* him. Hence, her husband's care needs supersede her own, which, as noted by Reverby (1987), remains consistent with traditional marital roles and social expectations. In addition, a study done by Monahan (1995) found caregivers feared not having enough money to provide ongoing care for their relative who have been placed in a long term care facility as their greatest source of stress. All of the participants expressed a sense of stress that comes from the limited finances left over for them to live in the community and the decision to continually *care for* their husbands by paying their high monthly long term care bills.

The quotes above regarding an older couple's finances remind social workers of not only the financial costs attributed to the one receiving care but also the sacrifices the elderly female spouses make daily to keep their husbands in long term care. The older female spouses' lack of household income reflects the lack of government funding provided for both them and for the long term care facility their husbands' reside in.

Additionally, social workers can recommend community supports to financially assist the caregiver still living in the community. Additionally, they may want to encourage female caregivers who are experiencing the same economic stresses to speak to one another, in order to support and learn from one another.

Cost Cutting Trends

As discussed in the introduction, the cost cutting trends for medical expenses clearly impacted 3 out of the 4 participants. In Ontario, the Ministry of Health and Long Term Care oversees all long term care facilities and therefore government funded and regulated (http://www.health.gov.on.ca/english/public/program/ltc/26_reporting.html). Although the government does provide a portion towards the overall cost of a ward room (4 persons to a room), it does not take into account the spouses remaining finances needed to live in the community. Thus the participants noted that they must contribute towards the cost of the husband's care in order for him to remain in the long term care facility. The monies older female adults do have to spend on food, shelter and their own ongoing medical care needs can become very limited (Statistics Canada, 2004) and the findings of this study support this.

The lack of funding provided to elderly persons in need of long term care, and the feelings of caregiver burden the participants note, reflect neo-liberal ideology as it seeks to limit the state's financial involvement in assisting with social and medical problems (Hill, 2008). The neo-liberal ideology of the state, of the Canadian government, appears to save the public monies by 'reducing' high medical costs however, realistically, the responsibility shifts to the individual citizen to pay for medical costs, particularly for long term care, rather than the universal health care system providing medical care. Similarly, Hill (2008) points out, it encourages the individual to shoulder more of the financial and emotional burden. Certainly this business approach is even more visible today given our current economic downturn. The state’s focus then is not on the quality of resident care or social processes of how care is provided but that of always calculating the amount it will cost to provide care. This cost cutting trend indisputably impacts most of the elderly women interviewed in a very real and consistent way. The participants certainly noted their own financial stress, but did not correlate this with the current government’s cost cutting trend to community services. Thus they did not recognize that this is a neo-liberal ideology at play, instead they saw it as their responsibility to simply *care for* their husband by contributing to the long term care costs. In *caring for* their husband, their own finances became very limited. Social workers would do well to advocate for elderly women’s needs for increased financial subsides at both the federal and provincial level. Additionally social workers may need to strategically and creatively find community resources to assist elderly women in maximizing their budgets.

Chapter 2: Caring About

In this chapter I will address the notion of *caring about* that is, the idea of showing love and affection towards one’s elderly spouse. In the introduction, the notion of *caring about* was discussed as part of the elderly females’ caregiving experience. One woman noted “Oh, yes, I mean I’ll kiss him when I go in and I always kiss him goodbye!” While the women themselves only talked about *caring for* their spouses, I have chosen to describe both caring *about* (showing love and affection) and caring *for* (practical tasks). I have separated these two concepts as they are noted individually in the literature (Finely et al., 1988; Guberman et al., 1992; Nolan et al., 1996). The following is a quote from one of the elderly wives regarding caring *about*:

> Oh, he tells me oh, I love you so much! You have no idea how much I love you! You know, you don't know how much he loves you! Maybe that's what makes me think I got to keep going every day, I don't know.

While the above quotation describes her husband's love towards her, one can also see how she questions how love is defined now that he is cognitively impaired. Similarly, she also acknowledges that his love for her motivates her, to keep on loving him. Another elderly woman stated the following, when asked how she *cares about* her husband in a physical way:

> Oh it went downhill, it went downhill! After the first stroke, he stopped being affectionate and that was the phase of where he was, you know, violent and he was so out of control! But even when that, we seemed to get that under control, he really distanced himself from the family and he...he...showed no affection to me and it was just like a you know a divided family!

Whereas the process of cognitive impairment began earlier for this second participant's husband (due to multiple strokes, as compared with the first participant's husband who was diagnosed with dementia much later in life), it is important to note that the above statements made by these elderly women reveal a sense of uncertainty regarding how they define the concept of love, now that their husbands have declined even further. Gladstone (1995) describes four themes in how couples perceive their marriage once their spouse has been diagnosed with dementia; marriage as a memory, the illusory marriage, the changed marriage and the unchanged or continuing marriage. Marriage as a *memory* is certainly echoed in the latter quote above. The participant made a reference to loving their husbands prior to their diagnosis and how she used to feel loved by him as well. She also notes how the marriage has changed in that her husband no longer knew he was actually married, due to memory loss and thus she reflects her 'marriage as a memory'. In Gladstone's study he found many spouses associated the "ending of their marriages with (the) loss of companionship or with the non-responsiveness of their husbands". This latter participant noted during the interview that as she lost her companionship with her husband, she no longer felt affectionate towards him. None of the participants stated their marriage had ended, but rather they emphasized how their marriages are no longer the same as when their husband was cognitively intact and living at home. Gladstone also notes that at the same time, the non-institutionalized spouse "emphasized the sense of responsibility that they continued to feel toward their husband" (1995, p.55). Feeling a sense of duty, or responsibility to continue to *care for* their husbands, is certainly apparent in the first woman's quote, as she commented on how she feels the need to keep on loving and visiting him when he states that he loves her. This participant still cares about her husband and would, I think continue to visit him even if he did not state how much he loves her. Gladstone goes on to say that, in his study, some spouses described their situations as being *illusory* because of the lack of emotional ties: as one participant said to me in this research project, "you are married, but you are not." This participant is referring to her sense of duty to continue to *care about* her husband in the nursing home. She also described later in the interview how she lives as a single person in the community. As a single person, she spoke of finding new single friends to socialize with, rather than hanging out with married couples. This elderly woman's observation reflects that one's identity is socially constructed by larger social norms, and in relation to the social identity of their cognitively impaired spouse, which in turn necessitates a change in the self identity of the caregiver (Andershed, 2006). Thus one's identity changes if the spouse's identity (as per social norms) changes as a result of cognitive impairment. Hayes et al. (2009) state that self-identity is fluid and vibrant and therefore, a joint effort between oneself and the other. Sabat and Harre (1992) purport that changes occur in the cognitively intact spouse's sense of self identity because of the perceived lack of social responses they experience from their spouse.

There is an implication here for social workers to be more consciously aware of the emotional work elderly female spouses do in terms of trying to construct or reconstruct their social identity (how they are perceived by others), on an ongoing basis. Even though these elderly female spouses felt emotionally distanced with their husbands, they still continued to show love by visiting and being with them, and in some cases displaying affection (i.e. hug/kiss). Elderly females may well need social workers to assist them in exploring various feelings and frustrations related to their now institutionalized spouse, in light of their evolving marital relationship. Cohen, Kennedy and Eisdorfer (1985) suggest that the cognitively intact spouse, as they react to the losses associated with the dementia experienced by their husbands, may experience the following: concern regarding their spouse no longer recognizing them, anger, guilt, sadness and separation from their sense of self, or, said differently, a change in their social identity. Cohen et al. are referring to the grieving process spouses may undergo as they try to cope with the constant changes a person with dementia experiences. This grieving process impacts how these women *care about* their spouse (that is they may or may not want to continue showing love and affection towards their spouse) which in turn affects their sense of self-identity within an evolving marital relationship.

Again, social workers are well situated to assist elderly female spouses to identify feelings and concerns affiliated with grief and work with them in terms of coping with the many losses. It may also be helpful for social workers to connect several elderly female spouses, who wish to discuss how they currently *care about* their spouse and the ongoing changes affiliated with this aspect of caring, in order for them to gain knowledge from one another.

Gladstone (1995) also addresses a spouse's perception of the ongoing changes occurring within the marriage due to the ever-increasing cognitive impairment of the spouse diagnosed with dementia. Aspects of change, due to their spouse's cognitive decline would likely include having to recount shared historical events. All of the elderly women I interviewed relayed the difficulty in carrying on an adult-like conversation with their spouse, due to their cognitive impairment and reported that as a significant loss. Their collective statements reflect that the losses they experience within the marital relationship, due to their cognitively impaired husband, directly affects how they *care about* their spouse. As their marital relationship evolves, their feelings and showing of those feelings becomes increasingly more difficult and strained.

Pruchno and Resch (1989) found that women were more likely than men to distinguish changes in their marital relationship when their spouse suffered from dementia. Furthermore, the stress associated with the caregiving process often continue even after institutionalization, has been well documented (Dellasega, 1991; Zarit and Whitlach, 1992). As mentioned throughout this paper, the notion of caring *for* and *about* one's elderly sick spouse is a traditional role for which women have been given approval. Noting the caregiver's gender remains important as it is a contextual factor in shaping the stress process

(Pearlin & Aneshensel, 1994). Pearlin & Aneshensel go on to say this stress process identifies the female caregiver as responding to socio-cultural expectations to *care for and about* their family members and also, as stated earlier in the finance section, speaks to an elderly females' access or lack of access to power and resources. These authors categorize stress in one of two ways. Firstly, spouses will endure more stress-arousing demands when there are changes in the cognitively impaired person, as mentioned earlier. Secondly, stress is activated through the caregiving process itself (i.e., a spouse has difficulty carrying on their own recreational activities). The tension here reflects back to the statement made by one of the participants earlier, who stated "You are married, but you are not" and also to that made by the other elderly woman who comments:

> And, I say to everybody, I'm a married woman, but I live a single life! And so, therefore…you have to pick friends that you have something in common with… and learn to go and do things you know.

This participant speaks to the process of learning to build new friendships as a single person. Later in the interview, both women reveal that this process of creating new friendships is not an easy one. This is likely due to the fact, that they feel obligated in a marital sense to *care about,* that is show love and affection to her husband (who continues to decline) and yet may not feel they want to reciprocate that, as they are trying to build new friendships as a single person. I will discuss the notion of reciprocity and how these elderly female spouses view their marital identity in greater detail in Chapter 3.

One elderly woman stated she bought a journal to leave at her husband's bedside, to remind both him and nursing home staff when she will be in to visit and when she will not be in to visit (due to her own medical appointments in the community). This female spouse noted (with a big smile on her face) that, after every journal entry, she adds "xoxoxo," meaning "love, hugs and kisses". The participant stated to me, that if she forgets to add those letters after her name, she will "hear about it from him!" The meaning of these letters remains significant for both her and her husband, who is in the middle stage of dementia. Loboprabhu, Molinari, Arlinghau, Barr and Lomax (2005) postulate that the "repetitive questioning and frantic clinging that some dementia patients exhibit with the afflicted spouse are not only attempts to hold on to the familiar, but may be efforts to repair the disrupted (marital) bond and recapture closeness between the spouses" (p. 165). I would add that the this participant mentioned above, who remains in the community, has also made an attempt to hold on to the familiar, by using well-known affectionate phrases (see above) in caring *about* her spouse.

Interestingly, another participant remarked that, due to her culture, they never displayed any affection in front of their children prior to her husband's cognitive impairment. When asked about displaying physical affection she observed:

> It was not there (showing physical affection) even before, because you know in certain countries, you don't go holding hands and hugging in public and all these things. No, but emotionally it's still there!

This woman's statement addresses the notion of culture and how it plays a part in the expression of *caring about* her husband. During the interview she admits to the feelings of *caring about* her husband, however the expression of such is disciplines by the rules of a particular culture. Downs (2000) and Lyman (1989) state that much of the research done thus far has neglected to focus on socio-cultural factors that influence both the person with dementia and their significant others. Furthermore, studies which identify research participants as simply black or white "obscure significant within group variation, the values, norms and beliefs attached to the experience of illness and *caring for* (and, I would add, *caring about*) elderly family members" (Smith, 1996, p.261, 262). While the participant who made the above comment is not Asian, her cultural experience is similar. Caregiving studies show that the Japanese culture has tremendous respect for their elders, which includes not showing any public affection towards them (Koyano, 1989). Koyano notes that Japanese often mask actual personal meaning or feelings because publically expressing them is likely to be condemned or criticized by others in their culture.

Therefore, this participant raises an important issue, namely the need for social workers and staff "to be sensitive to the interplay between cultural expectations and personal beliefs about caregiving" (Smith, 1996, p. 263). Although Smith (1996) refers to caregiving in general sense, I believe how spouses may or may not show love and affection, due to cultural expectations and personal beliefs, falls under this larger notion of caregiving. Social workers and nursing home staff alike can easily exercise power, and label an elderly female wife as not caring about her husband (once again placing her in a position of subordination), simply because they do not see her displaying love and affection in a manner which is largely accepted in our western culture but may not be in non-western cultures. Given this participant states her emotional connection with her husband is paramount, and may even surpass her need to display public affection, perhaps social workers - together with nursing home staff - can help couples like her by facilitating the provision of a private or, at least, a semi-private space where they can meet to socialize. It may be particularly difficult on a locked, dementia unit (in a nursing home) to find such a space, depending on the availability of space and the age of the nursing home building (which, if an older building, may not have been built with many private rooms). Perhaps another suggestion would also be to provide adequate chairs around the bedside such that female spouses (particularly on locked units) can sit together with their spouses and enjoy being with their spouse free from nursing home staff approaching and interrupting them. It would also be prudent to enlist the help of elderly women and their spouses (those who still can participate) in discussions around what might work, thereby utilizing power to support couples. Thus, the elderly female's voice, knowledge and experience would assist staff in determining what can be done to address this matter.

Chapter 3: Caring With

Reciprocity Within Marriage

In this section I will be discussing the concept of reciprocity, or *caring with* their husbands, within the ever evolving marital relationship when one spouse is cognitively impaired. The concept of reciprocity within a marriage involves the notion of give-and-take, with an emphasis on gratitude (Simmel, 1950). Lewinter (2003), notes that reciprocity marks the foundation of marriages, as well as the shared meaning of giving and receiving care, which in turn reinforces a person's "sense of common belonging and shared interdependence" (Graham & Bassett, 2006, p. 336). When one of the married persons is cognitively impaired, the caregiver, or cognitively intact person, might refer to their relationship as unidirectional (Lindemann, 2003). Said differently, their married life has been fractured and the person with dementia is unable to reciprocate (Perrin & Hazel, 2000). Once a person has developed dementia, they may be unable to reciprocate or the way they do respond has been so dramatically altered that in fact it is not considered reciprocity by their spouses. In conducting this research, one elderly female participant said this about the emotional and psychological changes that have taken place in her marriage:

> It was okay. I always had that final say and I would say, okay, we'll look at it this way and then that…but I went back to him (to make decisions). It's up to you now, right?!

Without a doubt, this participant speaks directly to the theory of give-and-take so evident in their early married life and how this has changed such that she views her marital role as 'unidirectional.' When referring to their differing roles within the family, this elderly female woman went on to say:

> It's there, I still would, you know, think of him, if anybody asks you know, he's still the head of the family. He is still here right! Although, I do all the decision making, because he can't make decisions, he's still the head of the family!

This elderly woman clearly articulates that, practically, she has to make all of the decisions in life, though they once shared this aspect of their marriage, due to her husband's dementia. She also notes the ongoing filial ties and sense of duty to her husband by naming him the head of the family, an action which reflects the influence of her culture.

Another elderly woman commented on how she (a pianist) and her husband (a drummer) used to play music together at their church, and how they would also go golfing together. Now when she sees him, she remarks:

> I try to tell him things that he'd be interested in, I have to tell him about who it is and explain who they are! You remember blah blah? Do you know what I'm saying? Then, I have to do it all over again! So, I play solitaire and I put the ball games on, but now he's not sure who's playing. But it's hard! You know when you go in, and you're trying to visit someone who can't hear you, can't see you, and you have to say who you are to start with, it's got to be difficult for them (her husband and all the

> other residents in the nursing home). Every once in while I get choked up like now (tears start to fall). But you get used to it… it’s a way of life.

This elderly women highlights her daily visits with her husband and how complicated her interactions with her husband now are, due to his dementia, as well as to his loss of sight and hearing. In sharing her story, she notes her own grief and loss of companionship as the activities she once did with her husband are no longer possible or are simply one-sided (i.e. playing solitaire on her own). Hayes et al. (2009) notes that those diagnosed with dementia “experience a dramatic decrease in their ability to participate in meaningful social interaction due to problems with thinking, remembering and reasoning” (p. 48). Despite the dementia, this elderly woman has found ways to spend time with her husband; however these activities continue to be unsatisfactory for her. Her grief related to his decreased ability to communicate and continued commitment to visit him daily is a part of her socially constructed sense of self. This elderly participant is responding to social expectations that is, she as a married woman feels a sense of duty and responsibility to visit and spend time with him. At the same time she grieves the loss of participating in shared activities which in turns shapes her own self-identity. The reciprocity once evident through the enjoyment in their shared activities has given way to a ‘unidirectional’ relationship.

When asked about the emotional and psychological changes in her marriage since her husband’s dementia diagnosis, one of the elderly participants stated this about her husband:

> Well as I say, when he use to be very sad at night time [in the nursing home] that really upset me for the rest of the evening! I mean, I just cried, because I felt, I felt, so sorry for him and also sorry for me too! I mean, I just couldn’t sleep! I just cried and cried! I did a lot of praying because I have a strong faith, so fortunately that has been great for me, to see me through you know different things in my lifetime. It has brought me through, so, I know it’ll bring me through this too! But it is, it’s very hard

> on your emotions! But as (husband's name inserted) would say, I never thought I would end my days like this, being separated from you! So, sometimes I'll say well you know everyone in here is separated.

This elderly female participant so eloquently speaks to the sharing of emotions, now that he resides in a long term care facility (i.e. crying due to being physically separated from one another) that occurs within their marriage since his placement. This quote highlights that even though her husband has dementia, he has lucid moments when he is able to very clearly articulate how he *cares about* and *with* his wife and how he longs to be with her. Another elderly woman added quite angrily:

> It's very hard! It's very, very hard! You love the person that they were! You're living with a stranger! None of your emotional needs are being filled whatsoever! And you have to learn…to put them on the back burner basically and to realize that this is going to be your existence!

In essence, in *caring with* their husbands, these participants do exactly what Kitwood (1990) states-providing care which necessitates high levels of empathy, imagination, flexibility of thinking and being there for one another. The two quotations above, also demonstrate how these elderly female participants are trying to adapt to their marriages and yet at the same time, struggling to do so. Consequently, they are continually adapting their own lives and expressing incredible empathy towards their husbands. There is an opportunity here, for social workers to engage elderly female spouses and discuss how they try to adapt and yet struggle with their husbands continued cognitive decline. Social workers need to be mindful that these changes are ongoing or fluid, and continue to shape the elderly female's sense of self.

Reconstructing Their Identities

In the information provided in the chapter thus far, one can also note evidence of stoicism that is, all the elderly females' simply state life is what it is and they have resigned themselves to *caring with* their husbands, for better or worse. Earlier, I noted Aronson (2006) refers to 'stoic noncomplainers' as an identity for which elderly females might anticipate approval, given our present political context. In addition, individual identities are discursively constructed in conversational interaction (Forbat, 2005; Adams, 2000). Forbat (2005) goes on to say the construction of one's identity may be viewed as a flexible, changing self in the present and continues to be co-constructed within the ever changing dynamics of the marital relationship. A study conducted by Graham and Bassett (2006) notes the relationship, that occurs between the cognitively impaired person and their spouse is poorly understood. These authors found several themes that spouses experience, when their spouse is cognitively impaired including: accepting and resisting the disease process, cooperating and being in conflict with one another and, finally, feeling a sense of togetherness and detachment. In all the above comments, the elderly females spoke to the complexity of their married identity in terms of making decisions, feeling a sense of inner conflict as their own emotional needs often go unmet, sadness and redefining the notion of 'togetherness' when they physically live in separate homes. In essence, how these elderly women *care with* their husbands or reciprocate emotions, thoughts and feelings, remain very unidirectional and frustrating for them, and continue to impact their own self identity.

While the above paragraph mainly addresses the elderly wife's perspective of their marital identity, one can also ascertain from the last quote the cognitively impaired husband's sense of self and also his sense of self as being part of the marriage. I'm referring to participant who noted that her husband stated he never expected to spend his last days separated from his wife. Another participant commented about how her husband always remembered their dog and sometimes would even briefly remark how much he enjoyed his time with their family pet. The comments this elderly female's husband made are noteworthy, as he has had multiple strokes and severe dementia. These comments reflect the growing body of research which affirms that persons with dementia may, in fact, retain a sense of self identity despite their diagnosis (Mills & Coleman, 1994; Sabat & Harre, 1992). Having worked in a hospital with chronic care dementia units for a number of years where patients are in the latter stages of dementia, I would agree with the authors' findings above. As a social worker on these units, I have seen firsthand how patients express their own sense of self, either by choosing to eat certain foods that they like or conversely spitting out those which they do not like. Perhaps one of the more striking things I have noted is how the patients 'light up' and smile as their family member approaches and, in watching them interact, I have seen the patient's sense of enjoyment. In this sense the spouse (patient) is reciprocating emotions and recognizing their marital partner, however due to their dementia, changes continue to occur in the married relationship and they may not be able to recognize a family member in the future. Karner and Bobbitt-Zeher (2005) add that the self identities of both the person with dementia and their caregiver will likely transform over time and marital relations are reconstructed within an ever changing social context that comes as a result of each individual's ever changing social identity. Social workers need to once again be cognizant of the ever changing diagnosis of dementia and how that in turn affects both the husband's and wife's ability to *care with* one another. Furthermore, it may be helpful for elderly females to have ongoing opportunities to speak with social workers regarding both their husband's cognitive and physical decline. Social workers may want to encourage female spouses to connect with other women, within the same care facility, to encourage and learn from one another. In doing so, the professional expert help of the social worker is lessened and instead the 'knowledge' that the elderly female women share amongst themselves is deemed valuable.

Sexual Intimacy

Intimacy, as noted by Moss and Schwebel (1993), plays a crucial role in lasting romantic relationships or in a married relationship. According to Renshaw (1984), marital intimacy can actually be further organized into 6 types of intimacy: emotional, social, physical, sexual, spiritual and intellectual. The participants have discussed emotional, social and spiritual intimacy thus far and in the following quotations they address sexual intimacy. Rubin (1983) states that emotional and intellectual intimacy is often considered a precursor towards physical and sexual intimacy, particularly for women. One elderly female participant made this comment regarding sexual intimacy prior to her husband's diagnosis:

> Well, I mean, when he was living at home, I mean, we had a good sexual life really! Up until of course he had that, that bad fall. Certainly, I would say, up 'till he was 80 years old and I'm 6 years younger than him, we certainly had good physical contact always!

This woman's observations reinforces several studies that have be done, which reveal that, in fact, some older adults do remain sexually active until a very late age, even when some type of dysfunction occurs (Pfeiffer & Davis, 1972; Bretschnieder & McCoy, 1988; Riess, 1988; Steinke, 1994). One participant and her husband (who I talked about elsewhere in regards to the influence of culture on expressions of love) only ever expressed physical affection towards one another in the privacy of their bedroom. Her earlier comments also speak to the notion of remaining sexually active later in life. When I did ask her about showing or displaying love in a physical way, she did not make any further comments. Again, this may be due to traditional cultural norms which discourage particularly females from discussing this matter publically.

As a person with dementia continues to decline, the ability to maintain sexual intimacy usually becomes a challenge. Mullan (1992) and, Pearlin and Aneshensel (1994) note that when one of the spouses has been diagnosed with Alzheimer's disease, it is difficult for the couple to remain sexually active. While the authors above speak to the lack of emotional intimacy, which in term leads to diminished sexual intimacy among caregivers and their spouses, they do not include the caregiver's experience and feelings regarding the loss of sexual intimacy, once they have placed their husbands, in their findings. Similarly, Hayes et al. (2009) remark that one of the issues married couples have in remaining sexually active is linked to the inability to reciprocate ideas and feelings. Their study found that for older women in particular, their sexual relations distressed them due to both a decrease in feeling a sense of closeness to their spouse and the cognitive/physical changes in their spouse who has dementia. Certainly, the following comments made by the elderly female participants I interviewed, confirm Hayes et al.'s findings. They also speak to how quickly the participants' sexual lives became disrupted due to their spouse's multiple and complex diagnoses and eventual placement in a nursing home.

One elderly woman said this about the lack of sexual contact she has with her husband, now that he is in a nursing home:

> Well of course, he has a chair (in his room) you know, you press the button and it brings him up because he'd like to get up. So, he's in that chair all the time, so, I mean, I just go over to him and put my arms around him and he puts his arms around me, we kiss and that's, that's about it!

When I asked about how this change has impacted her, this elderly participant went on to say:

> Oh yes! Yes! And you know that is something (sexual intimacy) you really miss! Now, I wouldn't know if (husbands' name inserted) would miss that because…I mean when you've had all that radiation, I mean a man is not able to have an erection after you know. So, I mean, up until he had all that radiation, yeah, we had a really good physical side to our marriage! I miss that (pause), I definitely do you know.

Another elderly woman, whom I also mentioned in Chapter 2 and earlier in this section, said that her husband stopped being affectionate towards her after his first stroke, and how she loved the person that he once was. This participant also mentioned that her own emotional, social and physical needs are put on the "back burner" and can no longer be reciprocated by her husband.

These two participants, along with a third woman I interviewed, all indicated that, apart from an occasional kiss from their husband, or a hug, their husbands did not actively try to pursue any sexual intimacy. The cognitive changes stemming from Alzheimer's disease and, as well, the physical changes that occurred to their husbands' bodies due to a stroke or cancer, are understood by the women to further complicate and challenge their ability to maintain sexually intimacy. Equally important is noting the sense of loss and ongoing grief both spouses may feel due to one spouse's cognitive impairment. Their grief and loss is as a result of the lack of emotional closeness which in turn marks a decrease in physical and sexual intimacy.

The last elderly woman I interviewed had a completely opposite response as compared with the others:

> Physically there's nothing (*laugh*)! He'd like it to be more physical! I know he would, just by the little things he's said! "Why don't you just get into bed with me!" and I said, no I'd better not, or we'll be in trouble because I'm not interested! I feel kind of…I'm not sure but I think they must have some place for conjugal visits like they do in jails. I think they have (these types of rooms in the nursing home) here.

In this case, her husband, despite his dementia diagnosis, very clearly indicates that he is interested in sexual intimacy but she reports feelings of indifference. Throughout my interview with her, I found she also commented on the lack of meaningful conversation and shared activities now that her husband lives in a nursing home, which as Hayes et al. (2009) notes may impact her desire to be with her husband. It is also interesting to note, that she equates the nursing home to a "jail" and wonders if there is a room where they can meet privately. From practice, I know very few nursing homes in the Hamilton area have a private bedroom where couples or families can be. In fact, the long term care facility this particular participant lives in does not have such a room (even though the building was actually renovated within the last 10 years).

Graham and Bassett (2006) found that when persons married to a spouse with dementia hang onto their expectations of reciprocity - that is, only focusing on the how the person was able to give-and-take prior to their diagnosis - then their focus can quickly change to *caring for* and *about* while *caring with* begins to fade away. Each of the participants articulated the complexity linked to decreased sexual activity. They noted, collectively, sexual activity no longer takes place, yet most of them also spoke to the incredible loss this marks in their married life. The lack of sexual intimacy changes how these wives construct their identity. As Hayes et al. (2009) note, the relationship between husband and wife has increasingly achieved more of a "mother-child" quality, and caregiver wives become "uncomfortable with physical and sexual intimacy" (p.57).

As a social worker working in a chronic care hospital, I have found that the loss of sexual intimacy is not often discussed with female elderly wives whose husbands are slowly deteriorating both cognitively and physically. In part, this reflects societal values and norms, in that sexual intimacy is a private matter between husband and wife (Bitzer, Plantano, Tschudin & Alder, 2008). When a person with dementia, however, starts exhibiting sexually inappropriate behaviour (that is, making advances or exposing themselves to others), it becomes a 'medical' issue, which the expert health team either in a hospital setting, or the nursing staff in a long term care facility discuss. The elderly women I interviewed did not report any sexually inappropriate behaviours. Unless they wished to address any sexual intimacy concerns with their social worker, which usually was not the case, it becomes a rather silent issue. Perhaps social workers, upon establishing trust within their working relationship with elderly females, can open up a space to invite elderly wives to discuss the link between their unmet emotional needs and diminished sexual intimacy. Particularly those that express how hard it is for them to cope emotionally and the great sense of loss it is for them.

Social workers who work in long term care facilities have an added opportunity to advocate on behalf of those married couples who do wish to have some privacy in a bedroom, (that is counter to neo-liberal governance; freedom from security cameras and staff interference), to incorporate such a room when long term care facilities are renovated. In addition, for those who are fortunate enough to have a private room in a nursing home or in a chronic care hospital perhaps health teams need to be more diligent about respecting their private space within the institution. It may mean signs need to posted on the door indicating no staff are allowed in for period of time and, the understanding among staff that if and when the resident or spouse need assistance from staff they will notify them at their convenience (pending an emergency). By giving residents and their spouses this decision-making power, and enlisting them to advocate for themselves, the approach becomes more ‘bottom up’ and lessens the incredible professional power staff have within institutions like long term care facilities and hospitals.

DISCUSSION

For the past few decades in Canada and the United States, health care costs have continued to rise an at exceptional rate and consequently hospitals expend much of their effort in trying to deal with this issue. A recent report noted that the care needs of 8 to 10% of all patients in an acute care hospital in Ontario and across Canada could be met in a long term care facility (Appropriate Level of Care Report, 2006). Policies, such as the Local Health System Integration Act (LHSIA, 2006), have also been implemented to minimize expensive acute care costs and to offload health care costs to community providers, such as the Community Care Access Center (CCAC). Aronson and Sammon (2000) note that the shift from institutional care, such as from hospitals to community--based services (homecare or long term care facilities), has resulted in less federal funding and given provinces greater "control of health service delivery" (p. 169).

Consequently, the growing number of senior citizens with complex and multiple medical care needs, who require a nursing home, are being 'pushed out' of hospital systems as quickly as possible. Similarly older adults living in the community, who once again require high levels of care in their homes through the CCAC, simply do not have access to consistent and regular health care due to diminished services (Ontario Health Coalition, 2008). In terms of neo-liberal ideology, this business model of care continually shifts the focus of responsibility to the individual citizen to bear the financial and material costs of care services. Thus, elderly people who are caring for a family member with Alzheimer's disease must pay for their family member to receive care in a long term care facility. In addition, they must pay for extra costs such as clothing, special foods, and transportation for appointments in the community. Penning et al. argue that the "trend toward medicalization community-based care (reflects) the insertion of a medical model of care in the community sector or governments in shifting the costs of medical and particularly hospital care to the community." (2006, p. 745).

As a result of these trends and of the 'costs' to spousal caregivers, as well as to those of the individuals with Alzheimer's disease, I focused my study on a group of elderly women who had had to place their husbands in a long term care facility, because they could no longer care for them in their own home. The elderly women I interviewed described in detail the incredibly complex and multiple care needs of their husbands. Given their own physical limitations due primarily to their age, they had had to make the very difficult decision to place their husbands in a nursing home. Additionally, they discussed how it was also the absence of sufficient care through family members/friends and CCAC that made it impossible for them to keep their husbands at home. These women did not want to place their husbands in care, however given that they had to; they continued to *care for* them as an informal caregiver. Their role as a female informal caregiver is in alignment with societal expectations of women as caregivers for their spouses, even after they have been placed in a nursing home. Throughout my thesis I have also highlighted the feminine ethic of care. Freedberg (1993) states, socially women continue to "define and redefine their identity in relation to a set of nurturing roles" (p.535). Neo-liberal ideology also reinforces this concept that women (whether spouses or daughters) ought to be caring for their relative regardless of the social supports they may or may not receive. Thus the elderly women continued to provide *care for* their elderly partners in a long term care facility and often felt guilty (as they are no longer able to provide care at home), in that they were burdening the health care system. These elderly women felt a sense of burden as society values and privileges citizens who are younger, healthier and financially contributing to overall societal costs (i.e. taxpayers). Not only are their husbands not able to contribute financially, but also the elderly women themselves cannot contribute and consider their husband a burden, as they cannot care for their husbands at home and are now a cost to society. These expectations and the feelings the elderly women proved important in how the women described and had come to understand their experiences of *caring for* their spouse now in a long term care facility.

The purpose of this study was to further investigate and give voice to a few elderly women, who do in fact continue to care *for, about* and *with* their husbands when in a long term care facility and how their experiences reflect a neo-liberalist agenda in health care. In the tradition of institutional ethnography, I have mapped out the elements and processes affiliated with how they care and love their spouse after placing them in a nursing home, in an attempt to further understand their lives as women living in the community and the events that occur during this social process (Campbell & Gregor, 2002). By highlighting their stories in relation to the 'top-down' approach evident in nursing homes, one can begin to make sense of issues of power, knowledge, capitalism, the economy, the state, policy and culture (Campbell & Gregor, 2002).

In terms of *caring for* their spouses, these women collectively noted the increased medical care needed for their husbands, due to dementia or a stroke, and that this care was far more than they were able to provide. Furthermore, the limited amount of care they received from CCAC and the absence of additional family members or friends made it extremely difficult for these women to sustain *caring for* their husbands at home. After making the difficult decision to place their husbands in a long term care facility, their role changed from the primary caregiver to informal caregiver. This change in roles dramatically altered their lives, as one elderly woman stated, "well, there's absolutely nothing similar, I mean it's a completely different way of life."

This new way of life speaks to the many changes these elderly women have endured, now that their husbands reside in public institutions. As a group, these elderly participants have learned to *care for* their husbands by negotiating their roles as informal carers within the long term care facility, by speaking with staff regarding their husbands' care needs (i.e. putting a sign above the bed to remind staff of special care needs or advocating for their husband to be up in the wheelchair more throughout the day). While these elderly women have the courage at times to speak to staff, De Montiguy (1995) reminds us that the professionals who work in a long term care facility continually exercise institutionally-mandated power. Therefore elderly spouses are predominantly left in a "social relation of dominance and subordination" (Campbell et al., 2002, p.22). This medical model apparent in the health care settings (long term care facilities and private homes receiving services) is becoming an increasingly unsatisfactory experience of care for patients and their family members (Aronson, 2003; Zimmerman & Dalbelko, 2007; Hill, 2008). The women I interviewed support these very findings. Most of the women commented on their dissatisfaction with high turnover rate of staff members and the exhausting process of establishing rapport with new staff members in hopes that their husbands will receive adequate or better care. These elderly women also noted the strained communication that exists between staff (particularly due to the high turnover rate and the staff shift changes), including very limited interactions with the residence's designated physician. Their frustration reflects a tendency for a relative to withhold information for fear of negative consequences from nursing home staff (Hertzberg & Ekman, 1996). As a result caregivers often check on the quality of care by visiting regularly (Willcocks et. al., 1987; Schwartz & Vogel, 1990). This was certainly true for all of the elderly participants I interviewed, as they visited daily (with exception of one who visited 1-2 times a week). Most of the elderly women highlighted their sense of guilt if they did not visit regularly, as well as the need to check on the kind of care their husbands were receiving. Visiting regularly speaks to traditional societal expectations of married elderly women, that is, by visiting daily they are trying to appear as the 'good wife and caregiver.'

The changes in their role, the new concerns and frustrations they experience in their new role, frustrates also their ability to meet societal expectations.

Finally in caring for their husbands, the notion of limited finances was certainly apparent. All of the elderly women commented on how expensive it is to *care for* their husbands by placing him in a nursing home. Consequently, after paying for their husbands' care expenses, the monies left for them to remain in the community became very limited. Three of the four elderly women had to downsize their homes just to accommodate their husband's expenses and all of them were concerned about their own health in the future and the expense that this too might incur for them. In terms of neo-liberal ideology, health care costs are offloaded to the individual and the lack of public funding for long term health care costs is evident.

In caring *about* their elderly spouse, I found that the elderly women had various responses in terms of showing love and affection toward their spouse. I discovered that the elderly wives tried to hold on to the familiar aspects of the marital bond, by greeting their spouse with a kiss/hug or leaving hand written notes for them. These elderly women continued to *care about* their husbands by displaying familiar acts of love and affection. These efforts as Loboprabhu et al. (2005) suggests, recapture or maintain closeness between spouses. Interestingly, I also found that one participant's culture influenced her marital relationship, such that historically, they did not show any physical signs of affection in public and that this did not change upon his admittance to the care facility.

Two of the elderly women stated that they were married, but living a single life in the community. This reflects the ongoing perception of their self identity as virtually single, yet at the same time identifying themselves as part of a married couple. Another elderly woman described how incongruent her perception of marriage is, with her actual lived experience. The notion of living alone in the community, while still being married, largely reflects the lack of emotional ties between spouses, due to the dementia and therefore their marriage appears and feels more like an *illusory* marriage (Gladstone, 1995). All of the elderly participants spoke to *caring about* their spouse within a constantly changing marriage, due to their husbands continued decline both cognitively and physically and the incredible emotional work required to cope with these losses. I discussed the notion of the elderly spouses' marital and self identity in further detail in the *caring with* section.

The final aspect of caring *with*, which I explored, refers to the give-and-take or reciprocity, both husband and wife experience within a marriage, when one spouse is cognitively impaired and living in a long term care facility. This aspect of marriage presented a gap in the literature discussed and, therefore, was especially important to include in my study (Graham & Bassett, 2006). In speaking with the elderly females, they very clearly noted, that although they were able to *care with* their husbands, their husbands were not able to *care with* them. Thus, the elderly female spouses own needs-whether psychological, emotional or physical- have gone largely unmet. They expressed grief as they recounted the loss of the once shared activities and meaningful social interactions they had, due to their spouse's dementia and inability to reciprocate. In many respects, their relationships with their spouses became "unidirectional"-as they alone are largely responsible for initiating and following through with interactions with their spouse-rather than reciprocal in nature (Lindemann, 2003). On the other hand, these elderly female participants also articulated the ways in which their husbands were able to *care with* them and expressed their own losses. Some of the elderly women noted that their husbands, despite being in the latter stages of dementia, were capable of telling them, that they love them, and detested being separated from them physically. The elderly wives perspectives of their changing marital identity often left them confused, saddened and with a constant need to question and reconstruct their own identity. Defining one's role within the marriage, when a spouse is cognitively impaired and lives in a separate home continues to be a complex issue for elderly caregivers.

Lastly, and perhaps the least of all areas discussed in the literature is the loss of intimacy, between this group of women and their spouses,' particularly sexual intimacy (Rubin, 1983). This research study adds to the literature significantly in that it supports the existing literature. It also adds a new dimension, that is, the loss of sexual intimacy affiliated with a spouse who is cognitively impaired and cannot reciprocate sexual intimacy, after they have been placed in a long term care facility. Physical or sexual intimacy is largely linked to emotional and intellectual intimacy, such that as the latter starts to deteriorate, physical or sexual intimacy will also decline (Rubin, 1983; Mullan, 1992; Pearlin et al., 1994). My study concurred with Rubin's findings. While Mullan (1982) and Pearlin et al. (1994) describe the loss of sexual intimacy between a married couple, they did not elaborate on the caregiver's experience once they have placed their spouse in a long term care facility. In fact, three of the four women no longer desired physical or sexual intimacy after they placed their husbands in a long term care facility. They noted that this aspect of their marriage started to decline as their husband's medical care needs started to increase, just as Rubin (1983) suggests, a process which began well before their spouse entered a long term care facility. One of the elderly female participants stated the opposite and in fact described a sexually active relationship just prior to her husband's admission to a nursing home. In all cases however, each of the elderly women expressed their feelings of incredible loss with respect to this part of their marriage and how it is just one more of the losses they have to endure given their husband's health status and placement in a long term care facility. Interestingly I found, that all of the women were quite eager to discuss this aspect and did not hesitate in any way, (with the exception of one participant who, for cultural reasons, had never publically discussed this topic).

Throughout my findings, I have indicated how social workers and elderly female spouses (along with their husbands, if they are still able to participate) might work together at the micro level to implement small changes within the long term care facility. By implementing these small interventions, such as addressing their direct concerns regarding the care their husband receives and including their knowledge, expertise and experience into the decision making process, one can begin to challenge the 'top down' approach inherent in long term care facilities. Thus, I have also addressed the need for social workers, along with nursing home staff, to be more cognizant of the professional power inherent in their relationships with informal, female caregivers. In doing so, they can minimize their professional decision making power and begin to consider/include each female elderly spouse's personal and cultural preferences. Therefore, social workers are also in a position to advocate for an attitudinal change, and understanding of the elderly female's caregiving experience among staff, and this would directly impact their practice in a long term care facility. Similarly, it would also be important, to provide the elderly female's knowledge and experience to the staff and social workers working in a long term care facility. All of these suggestions are an attempt to bring the voices, knowledge and expertise of the elderly female spouses I interviewed, to the foreground with regards to their husbands' care in a long term care facility.

Reflections

I noted earlier in my methodology section, that the age difference between the participants and myself, and similarly, my lack of direct caregiving experience, might pose a difficulty in coming to my understanding of their experience. In fact, I found this was not a problem at all and the opposite to be true. The elderly women I interviewed were, in fact, quite keen to speak with me and to tell their story, even though they knew I was both a social worker and a research student. Although at times I wanted to take up the ‘good’ or ‘wife’ caregiver discourse, I chose to listen instead. I had originally allotted 60-90 minutes for each interview and quickly realized these women wanted to engage much longer in conversation and, therefore, interviews lasted as long as 2 hours. When I thought the interview was complete and I had turned off my tape recorder, each one of the participants started to speak again regarding their situation, such that I had to turn the tape recorder back on and sit down to listen once more. I believe the participants felt it was extremely important that their story be heard and utilized for social research, such that other female caregiver’s might learn from their experience.

Throughout the interview process, I found that, as a social worker, I wanted to address some of their losses, and reassure them they are doing the best they can, given their often hard and complex circumstances. I chose, however, to remain mostly quiet and to listen. I reminded myself that in this situation, I was acting in the capacity of a researcher and there to ask a few questions, and I was not there as a social worker. In choosing to ask the four elderly female participants to share how they *care for, about* and *with* their spouses, their wealth of ‘knowledge’ became paramount and counted as the ‘evidence’ and, as a result, there was less focus on the ‘knowledge’ of the researcher.

CONCLUSION

While I only interviewed a very small sample (four women), it has become clear to me that these elderly female participants were interested not only in telling their story but in contributing to social research. With only 4 participants included in this study, I have limited my ability to generalize and have only begun to address the elderly female caregiver's experience. Nevertheless, I do believe that this research study has value. My research has certainly contributed to my own body of knowledge on the caregiver's experience; however I am hoping that it will also assist other social service providers. One can also derive implications for social workers working in hospitals and in the community, who often help female spouses transition into long term care facilities, and the caring team who work within a long term care facility (i.e., health care professionals and administrators). I have utilized an institutional ethnography perspective and a critical approach to outline throughout my thesis that long term care facilities still uphold a top-down approach, through their "ruling" routines, practices and policies (Campbell & Gregor, 2002). In highlighting the stories of these elderly spouses however, it is my hope, that social service providers will raise their awareness of the valuable knowledge elderly female spouses have. This in turn might well improve their practice and begin to lessen the power imbalances inherent in staff/family interactions. In addition, social service providers, along with social workers, have an opportunity to address and challenge social policies. Specifically, they can address socioeconomic policies that control funding of long term care policies and long term care policies around responsibilities for care and hierarchical arrangements, which continue to keep elderly female caregivers predominantly in a position of subordination.

Future Research

If I continue with my studies, I have considered taking up the same question and interviewing additional participants (until I reach saturation) and to submit an article for publishing. I believe, it is important to conduct future research, because the limited existing studies regarding elderly persons, who have placed their spouse in a long term care facility, say little with regards to “the nature of older marriages in the later stages of life” (Gladstone, 1995, p.52). Further research with this same population might also include, conducting a longitudinal study that would provide additional insight into the older female spouse’s experience later in life. Now that I have completed my research, I have become aware of additional questions I would like to ask. Additional probing questions would include: how has *caring for, about* and *with* your husband changed in the last few years, how has your husband’s *care for* you altered in the last few years. It would be interesting, as well, to return at a later date to the four women I interviewed here and to explore any additional changes that occurred in their relationships over time (for example is their current relationship similar or different since the first interview. Finally, still further research could also begin to explore the elderly female’s experience once her husband is deceased and how she transitions into widowhood. By researching the elderly female spouses’ experience over time, which would eventually include her husbands’ death and subsequently bereavement, such as Pearlin & Aneshensel (1994) did, one can view their experience more holistically and along the continuum of care.

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APPENDIX A

LETTER OF INFORMATION / CONSENT

A Study of/about: The experiences of older female caregivers who currently have a husband living in a long term care facility.

Investigators:

STUDENT RESEARCH

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Purpose of the Study

You are invited to take part in this study on the experiences of caregivers in caring for their spouses who now reside in a nursing home. I am conducting this research project for my Master’s of Social Work and would like to learn more about your role as a caregiver now that your husband lives in a nursing home. I am also hoping to find out more about how the nature of your relationship has changed both in a practical sense and emotionally / physically since your husband’s admission to a nursing home.

What will happen during the study?

The research study will involve one 60-90 minute, face-to-face interview either in your home or at a mutually agreed up on setting. During the interview, with your permission I would like to use an audio tape and keep handwritten notes. I will also ask you for some demographic information like your age and how long you have been married.

I will be asking you questions such as:

1. Describe how you cared for your husband before he went to a nursing home and now that he lives in a nursing home?
2. In describing how you have cared for your husband, how has he and how does he now care for you?
3. How has your relationship changed or stayed the same both emotionally and physically?

Are there any risks in participating with this study?

The risks involved in participating in this study are minimal. You may feel uncomfortable, upset or sad after sharing your story with me. If you find that you are emotionally upset after the interview, I would suggest you contact the Family Connection. I will provide you with all the contact information on a sheet I have prepared for this study.

You do not need to answer questions that you do not want to answer or that makes you feel uncomfortable and you can withdraw from the study at any time. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study?

The research will not benefit you directly. You may find however, through sharing your story it will help you think through your own experience. In addition, your story or care giving account might assist other caregivers and professionals in the community.

Payment or Reimbursement

I want to thank you for participating in this research study by giving you a Tim Horton’s card (value $5).

Who will know what I said or did in the study?

Every effort will be made to protect (guarantee) your confidentiality and privacy. While I, the researcher know your identity, I will not use your name or any information that would allow you to be identified in my report. The information/data you provide will be kept in a cabinet in my home where only I will have access to it. Information kept on a computer, in my home office will be protected by a password. Once the study has been completed, I will keep the data in my locked cabinet in my office for no more than 5 years, after which time, it will be destroyed.

Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information related to elder abuse. If you do disclose elder maltreatment a report to the Hamilton Police will be made.

What if I change my mind about being in the study?

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect the services your husband receives at the nursing home.

How do I find out what was learned in this study?

I expect to have this study completed by approximately June 2010. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or require more information about the study itself, please contact me. My contact information is located at the top of this letter.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Caroline Sears, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: ___________________________________

Name of Participant (Printed) ________________________________:

1. I agree that the interview can be audio recorded with hand written notes.
... Yes
... No

2. ...Yes, I would like to receive a summary of the study's results. Please send them to this email address ________________________________ or to this mailing address

____.

.....No, I do not want to receive a summary of the study's results.

3. I want my identity kept confidential.
...Yes
... No, I prefer to be identified or have a pseudonym used.. Please refer to me as

____

4. I agree to be contacted about a follow-up interview and understanding that I can always decline the request.
*... Yes. How to contact me*______________
... No

APPENDIX B

Interview Guide:

1. Describe how you can care for your husband, now that he is in a nursing home?
2. How is that different from or similar to when he was living at home?
3. You talked about care giving for you husband, how does he now care for you?
4. How has your relationship changed or stayed the same emotionally and physically, now that your husband resides in a nursing home?
5. Is there something important we forgot? Is there anything else you think that I need to know about your care giving experience?

APPENDIX C

Help Sheet

If you are feeling upset after our interview is complete, please do not hesitate to call:

Insert – Name of Social Worker

Insert – Name of Long Term Care Facility

Insert – Phone number and ext.

In addition, if you have access to the internet, you may want to look up the following website: www.von.ca and click on Caregiving and then click on Caregiver's Connect. This website allows you to register as a caregiver and email fellow caregivers or professionals regarding your experience or questions you may have.

You may also want to contact:

Alzheimer's Society
Family Support Services
1685 Main St. West
Hamilton, Ontario
L8S 1GS

905-529-3787