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The Use of Stories and Photographs to Explore Senior Caregivers' Experience of Caring for a Spouse at Risk for Falls

by

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Abstract

This study is intended to contribute to improvements in nursing practice and client outcomes through the enhanced understanding of professional nurses about individual experiences, specifically older people caring for spouses at risk for falls.

A qualitative narrative approach using two relatively new methods, visit and interpretive photography, were used as research tools. Using a purposeful sample of caregivers from the control group of a larger quantitative study on falls, four seniors of spouses who had experienced a fall were contacted. Repeated visits built the relational narrative and the photographs provided further depth. Analysis identified the shared experience of the significance of the fall(s), sacrifice of self, marital discord, and supportive relationships.

The implications for nursing are identified in terms of clinical, research and education in light of the research narrative accounts. The outcome is a grounding of nursing care that is based on expanded understanding of older adults.

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CHAPTER ONE: OVERVIEW OF THE STUDY

Introduction

Although considered young in comparison with other countries, since 1987 Canada has met the World Health Organization's standard of being 'old' because 10% of its population is over the age of 65 years (WHO, 1990). Persons 65 years of age and older are the fastest growing segment of the Canadian population and their numbers are expected to increase as the post-war baby boomers age, to an estimated 25% by the year 2031 (Beckingham, 1993).

The increase in the older population impacts on many areas of social and economic development including health, social, cultural, and economic policies, housing and living arrangements, and resource allocation. In order to prepare to meet the needs and challenges of this expected growth and to practice effectively, "gerontological nurses must be aware of both the changes that are taking place in Canada's older population and the impact of numerous factors on the health and health care of older adults" (Beckingham, 1993, p.5). In regard to these various issues, the maintenance of independent living by seniors in the community is one factor that will be explored further in this research.

In keeping with government policy, as well as the preference of seniors themselves, community residency continues to be the most common living arrangement for the majority of seniors. However, many of those seniors require some type of assistance to maintain their independence and family members, in particular spouses, often take on the responsibility for this assistance. In 1987, an estimated 270,000 seniors required substantial assistance with activities of daily living in Canada (NACA, 1990). It is expected that this number will rise dramatically to 1.5 million in the next thirty years, thus likely increasing seniors' need for caregiving assistance.

Background and Significance of the Problem

It is estimated that family and friends provide between 75% to 85% of the help received by seniors needing care in the community (NACA, 1990). Although there is a plethora of literature on caregiving, particularly the aspect of burden, little research has focused on the senior spouse or significant other (Novak & Guest, 1992; Palo-Stoller & Cutler, 1992; Pruchno & Resch, 1989). Similarly, a substantial amount of research has explored various aspects of accidental falls among the senior population (Elford, 1994; Herndon, Helmick, Sattin, Stevens, Devito, & Wingo, 1997; Lilley, Arie, & Chilvers, 1995). However, few researchers have examined the impact of falls on spousal caregivers. This critical area traditionally has not received the attention it deserves. The statistics on the incidence of falls among the elderly alone make this an area of interest and concern for researchers. Falls are not only a common problem, they are the leading cause of accidental injury and death in those 65 years and over (Statistics Canada, 1994).

The rate of household accidents resulting in activity-loss days is unusually high for persons 65 years and older. According to Statistics Canada (1994), the rate is 775/ 1000, double that of persons aged 15-24, who are at higher risk for accidents. Falls often result from, and can lead to, further decline in self-care abilities. A syndrome called the "fall cycle" can develop whereby following a fall seniors may be frightened or reluctant to mobilize or participate in their usual activities. As a result of this sedentary lifestyle, muscle wasting, joint stiffness, and bone degeneration can occur. This cycle puts seniors at an even greater risk of injury should they accidentally fall (Jewell, 1997; Morse, Tylko, & Dixon, 1985; Vellas, Wayne, Romero, Baumgartner, & Garry, 1997). Were it not for the care provided by their spouses, many seniors would find themselves unable to maintain their independent living.

Alternative living arrangements depend on a variety of factors, including support systems available, but often the options are limited to choosing between a lodge or a nursing home. For those seniors who are more financially secure, caregiver stress and burden can sometimes be avoided or lessened through private employment of home care personnel. This scenario does not represent the majority of seniors however.

To better understand, assist, or intervene appropriately, nurses must try to comprehend the fragile and vulnerable reality in which many seniors currently live. In this attempt at understanding, further thoughtful questioning invites inquiry into areas that have not yet been previously explored. Bergum (1989) states, "with questions that search for understanding, there can be no separation of the knowledge of the experience from the meaning of the experience. That is, understanding the meaning of the experience can be understood only by reflecting on the context of the situation" (p. 56). This assumption is echoed by Omery (1983) who suggests that in order to describe the subjective lived experience of the individual, the person's perspective and the effect of that perspective must be understood. This view forms the foundation upon which this research was developed. To gain a richer understanding of the caregivers' perspective, this study explored the experience of being both spouse and caregiver of a partner with a history of frequent falls. To this end, a qualitative approach using a relational narrative method called "visit" (Running, 1997), was combined with interpretive photography to facilitate and enhance the creation of the caregivers stories regarding their unique experience.

Coming to the Question

My interest in the caregivers' experience started several years ago, while I was working as a staff nurse on a combination Renal and GAU (geriatric assessment unit). On this unit I encountered, and cared for, seniors who required assistance in achieving a level of wellness to enable them to return home. For many seniors, it was the need for physical rehabilitation following a fall or series of falls. The unit staff worked with seniors with the intention of discharging them home, often to a caregiving spouse. As a nurse working with these seniors, I often wondered what to tell the spouses or other family caregivers that would help to make their lives easier. What did they need to know? I was familiar with the literature on caregiving and understood it to have both burdens and rewards. I was also aware that much depended on the care recipients' level of dependence for personal care needs or their stage and type of dementia symptoms. I endeavored to help the seniors to reach the level of independence they came in with so not to further increase the burden on their caregivers and to help the seniors maintain a sense of well being and increased self-esteem through regaining their independence. Thinking about the seniors returning home, and the caregivers who would continue where I left off, planted the seeds of my question.

My question began to really take shape and "flower", to continue the plant analogy, when I participated as a research assistant in a large quantitative study examining interventions to prevent falls in seniors living at home. Visiting the homes of seniors, I was in contact with several whom were looked after by a spouse. Also known as the "hidden patients" (Fengler & Goodrich, 1979), spousal caregivers are often forgotten, lost in the shadow of their loved one's crises. I wondered what their experience was like. Because the study had falling as a focus, it encouraged me to research what I could on caregivers of spouses at risk for falls. Unable to find anything in an extensive literature review of this not uncommon experience, my question was formed, what was the experience like for these caregivers?

Purpose of the Study

My review of the literature on caregiving revealed a gap surrounding the experience of spouses living with partners who have had a fall and are therefore at risk for falls. This paucity of literature on falls and caregiving was intriguing and one worthy of further examination. Part of the reason for this inquiry was its importance in fostering nurses' understanding of the experience of living with a spouse who falls, thus enabling them to care more effectively for this population. The purpose of this study was to explore and explain individual senior caregivers' experience of living and caring for spouses or significant others who are at risk for falls.

Introduction to the Method

As a nurse I had listened to many of my patients' stories and, recognizing their value, I sought to listen carefully in an attempt to understand better the person for whom I was caring. In searching for a method that I believed would best explicate my research question, I looked for something that would also match my interest in stories as a form of communication. Qualitative methods seemed to fit with this type of inquiry. As Boykin & Schoenhofer (1991) describe, "Nursing scholars are persons in a constant and common search for understanding the content of nursing.... Nursing cannot occur from the exterior. It only occurs through entering the world of the person(s) being cared for, understanding that world and the calls emerging from it, and responding to them"(p.247). Thus "Visit" became the method of preference.

'Visit' (Running, 1997) is a type of narrative approach that respects the participant as an expert. The researcher's voice becomes woven into the fabric of the narrative or story as it unfolds. It is for this reason that Running refers to the participants as co-participants, but they could just as easily be referred to as co-researchers, as they are completely involved in the research process. The co–participants stories evolve out of several meetings and reviews of previous transcripts. Together researcher and participant decide what best tells their story of their experience, and then decide when their story has been fully told. Questions evolve from the visits and are open-ended requiring participants to expand on their responses.

Combined with this relational narrative approach is interpretive photography. Long used in other disciplines like anthropology, photography is gaining popularity in the nursing arena as well. Having read other studies that employed photography as a means of eliciting data, I was intrigued. I thought that perhaps an additional opportunity for description might be helpful in assisting seniors to describe their caregiving experience.

Significance to Nursing

Understanding what it is like to care for a spouse who has fallen and is at risk for falls helps nurses better care for both family members when the care event is initiated. Often in crisis following a traumatic event such as a fall, caregivers can go unnoticed, unheard, uncared for. As I was to be reminded, nurses must think of the couple as a dyad and nurse them accordingly, otherwise one spouse may be replaced by the other, so fragile is their independent coexistence. Understanding the caregiver's experience helps nurses to recognize the complex and unique needs each caregiving dyad presents with.

Nurses are in a unique and privileged position of trust that allows patients and families the safety of sharing their most private concerns. The act of hearing and responding to these concerns is at the heart of what nursing is all about. Sharing these caregivers' experiences allows others to see the ordinary yet extraordinary world these couples live in. A window into the lives of a vulnerable population is opened. Through this window, new insights and learning occurs about the multifaceted crystal that caregiving represents. It allows nurses to be reminded not only of the value of stories and photographs used as a method in this study, but also of the importance of attending to the "hidden" patient as well as the patient in the bed.

Assumptions

Because I had chosen a qualitative method to study my research question, I was reminded of the importance of examining my personal beliefs and assumptions prior to embarking on my study, as has been well described by researchers in this area (Struebert, & Carpenter, 1995; van Manen, 1984). By revealing deep-seated beliefs and assumptions, I could approach the study more openly and honestly. Having insight into one's own assumptions can also help avoid careless judgments. The following are the assumptions that guided me throughout this qualitative study:

1. The experience of caregiving is a topic worthy of study.
2. Meanings are both found and created within the experience of caregiving.
3. These caregiving experiences can be communicated both verbally, through communication, and non-verbally, through photographs.
4. Participants will be willing and able to engage with the researcher in the creation of relational narratives.
5. The nurse researcher, as a co-author of the relational narrative, brings her own life experiences and worldview regarding aging and caregiving, to both participate in the production of the relational narratives and account for them in the written text.
6. The nurse, in the narrative relationship, values the person as, "a human being who transcends all generalization, an individual whose body expresses itself as a reality with its own unique meanings and values" (Gadow, 1979, p.91).
7. The privilege, and challenge, for nurses, is to assist clients in developing the meanings emerging out of their experience, and not allow them to be subsumed by medical jargon and sterile clinical interpretations (Gadow, 1979; 1980). This philosophy is congruent with that of qualitative approaches in general, but speaks clearly and directly to the qualitative approaches used within this study.
8. The nurse, within the parameters of this special relationship, can assist clients to recognize, and lend insight into, the multiple possible meanings of the phenomena to which the client is exposed (Running, 1994, Gadow, 1994).
9. These relational commitments between the nurse and the client are essential in discovering and empowering full disclosure of the client's experience and the meaning of the experience to the client (Running, 1997, Watson, 1985).

10. Inherent in this relational commitment, is the belief of the "client as expert". The client is the embodiment of the experience and the meaning of that experience can only be disclosed by them.
11. Within the dyadic relationship, persons are "empowered to reflect on, and talk about, their lives, making a variety of connections with other events in the past, present and future" (Running, 1997, p.119).
12. The nurse's own life history and previous experiences and opportunities of having lived through or experienced one's feelings and various human conditions, and of having imagined others' feelings in various human conditions is essential in the process of the narrational relationship (Watson, 1985).

These assumptions guided the development of the proposal, and the research study as it progressed.

Summary

A major health problem for seniors, falls are a serious, and unfortunately not uncommon, concern. Little research however has recognized the subjective experiences of caregivers caring for partners at risk for falls. In this chapter the research problem was described, including the significance of the problem to nursing, the methodological perspective used in the study, and the assumptions guiding the study. In Chapter Two, the literature pertinent to falls and caregiving is reviewed. In Chapter Three, the methodology used in this study is described and in Chapter Four the narrative accounts of the couples are presented. The analysis of the accounts are discussed in Chapter Five. Chapter Six describes the implications for nursing, research, and education and the conclusions of the study.

CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction

A review of the literature revealed that studies on falls have been done primarily in institutional settings, have generally been quantitative in nature, and have focused largely on identifying risk factors and causes of falls. To date, the bulk of the research on falls has focused on the person who has fallen, or is at risk for falling. It appears that there has been very little research in the area of the experiences of senior caregivers of spouses with a history of frequent falls. This literature review focuses on two primary areas: falls and senior caregivers. Each of these areas will be addressed in turn.

Falls by Community-dwelling Seniors

Falls by the senior population are the most common cause of accidental injury and death (Elford, 1994; Lilley et al., 1995; Morse, Tylko, & Dixon, 1985). Herdon et al. (1997) identified multiple falls as being associated with an increased risk of mortality. Frequent or recurrent falls have been noted to be indicative of increasing frailty with further deterioration and decline of health status (Suzuki, Shimamoto, Kawamura, & Takahasi, 1997; Tinetti, M. E., Baker, D. I., McAvey, G., Claus, E. B., Garrett, P., Gottschalk, M., Koch, M. L., Trainor, K., & Horwitz, R. I., 1994). Falling, and resulting fear of falling, reduces the quality of life (Herdon, et al., 1997; Vellas, et al., 1997). Studies have shown that older women, in particular, are at high risk for falls and injuries (Elford, 1994; Ryan & Spellbring, 1996; Suzuki et al., 1997).

Falls are generally diverse in cause, but certain risk factors have been identified through research. These factors include: muscle weakness, balance impairment, medication usage (particularly psychotropic drugs, laxatives and diuretics), dementia and other cognitive impairments, self care difficulties, and advanced age (Rossy, D., Jourdain-Grand, S., Lamb, G., Armstrong, E., Athrens. S., & Berry, J., 1997; Tinetti, et al., 1994; Morse, Black, Oberle, & Donahue, 1989). Normal aging processes such as loss of vision, hearing, and other sensory perception, decrease in bladder capacity (necessitating more frequent and urgent trips to the bathroom), loss of bone and muscle mass (contributing to vertebral weakening and a general propensity to fractures), gait changes and reduction in proprioception, all put seniors at risk for falls (Beckingham & Dugas, 1993; Lilley et al., 1995; Morse, Tylko, & Dixon, 1985).

Whittle and Goldenberg (1996) note that as health declined in the seniors they studied, more assistance was required with tasks such as housekeeping and shopping. Means of transportation, essential to day to day household management, also became a concern as frailty and activity intolerance increased. Health declines impact both the care need requirements and division of labour for household management. Tasks performed by the frail spouse prior to the illness must now be addressed by the spouse whose level of wellness is currently the better of the two. Out of all the issues delineated by the research, most frequently cited was the seniors' need for assistance (Ade-Ridder & Kaplan, 1993; Fengler & Goodrich, 1979; Novak & Guest, 1992 ; Wilhoite & Buschmann, 1991). Spouses have been found to be the first line of defense in coping with dependence due to illness and disability (Horowitz, 1985; Stoller & Cutler, 1992; Shanus, 1979). Advanced age, health decline and mobility difficulties all may lead to the need for spouses or significant others to assume the caregiving role.

Senior Caregivers

For some seniors, an important anniversary such as the "golden" or fiftieth anniversary may also mean the beginning of a period of caregiving to a disabled or debilitated spouse (Ade-Ridder & Kaplan, 1993; Brubaker, 1985; Fengler & Goodrich, 1979). Although women continue to represent the largest number of caregivers, research in the last 10 years has shown that both men and women act as caregivers to their spouses (Barusch & Spaid, 1989; Gregory, Peters, & Cameron, 1990; Stoller & Cutler, 1992; Pruchno & Resch, 1989).

Family members provide for nearly all long-term care needs of frail seniors living in the community (Browning & Schwirian, 1994; Shanus, 1979; Smith & McCallion, 1997). The abundance of both qualitative and quantitative research on caregiving demonstrates the importance of caregiving as an issue within nursing practice.

A great deal has been written both, qualitatively and quantitatively, about the caregiving experience of spouses and other family members caring for seniors with Alzheimer's disease and other forms of dementia (Pruchno & Resch, 1989; Boykin & Winland-Brown, 1995; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Ostbye, Tyas, McDowell & Koval, 1997; Novak and Guest, 1992; Pratt, Schmall, Wright, & Cleland, 1985) as well as disabled and frail seniors (Fengler & Goodrich, 1979; Harvath et al., 1994; Smith & McCallion, 1997; Shanus, 1979). Issues involving gender and caregiving are also discussed in the literature (Allen, Goldscheider, & Ciambrone, 1999; Gregory, Peters, & Cameron,1990; Pruchno & Resch, 1989, Rutman, 1996; Barusch & Spaid, 1989). Findings from these and other studies pertinent to this study are described below.

Shanus (1979) in her seminal research on the role of family support for seniors, identified the reliance of spouses on each other for caregiving assistance when one is unable to manage independently. This finding is later echoed by Horowitz (1985). Pruchno and Resch (1989), examined depression in caregivers caring for spouses with Alzheimer's disease noting differences between husbands and wives. Findings noted that wives were both more depressed and burdened than husband caregivers, Husbands were more likely to receive outside assistance and support for caregiving tasks, and were more depressed if they were experiencing ill health. Also studying gender and caregiving, Barusch and Spaid (1989) in their quantitative research, studied the impact of gender on caregiving configuration, finding that married persons requiring assistance with activities of daily living relied on their spouses first and, similar to Pruchno and Resch, that the male caregiving spouses were more likely to employ outside assistance with caregiving tasks.

More recently, the relationship of gender roles and marital intimacy has been examined as well. Braithwaite (1996), noted that the relationships changed between the caregivers and receivers with the new relationship superimposed upon the previous one. She insightfully comments that these previous relationships may in fact, "not lend themselves to transformation" (p.144) That is, if the marital relationship was in trouble prior to the onset of the caregiving event difficulties may continue and could be exacerbated. Fengler & Goodrich, (1979) postulated that since women live longer than men, usually marry spouses older then themselves, as well as societal expectations, women were more likely to be caregivers for spouses. They therefore interviewed elderly wives caring for disabled husbands. Their findings suggested that the caregivers were exhausted with their extra duties, aware of this, care receiving spouses felt "helpless" with one spouse even wishing he were dead so as to relieve the burden he perceived his spouse to be under. Pruchno and Resch (1989), noted that husband caregiver were more invested in the marital relationship than the wives were. "Husbands expressed a greater sense than did the wife caregivers that the care they were currently providing their spouses was due to them" (p.163). Kramer and Lambert (1999), in their longitudinal quantitative study of older husbands, found that husbands who had become caregivers during the time of the study experienced "significant changes in their household tasks, social integration, marital relationships, and wellbeing" (p.665). Particularly, they noted that the caregiving husbands reported significant decline in marital happiness and more perceived their marriages to be in trouble than the non-caregiving husbands. Allen, Goldscheider, and Ciambrone (1999), studied spouses undergoing cancer treatment utilizing their spouses as caregivers. Findings reported that, "although gender role norms are key to caregiver selection, the intimacy inherent in the caregiving role renders an emotionally close marriage an important criterion to the selection of spouse as caregiver"(p. 150). In addition, all of these key concepts have been studied in their relation to caregiver burden and are describe below.

Caregiver burden or burnout, also referred to as emotional strain, and role strain, have been studied in their relationship to gender differences and a number of other variables such as age and health (both mental and physical) (Barusch & Spaid, 1989; Gregory, Peters, & Cameron, 1990; Pruchno & Resch, 1989; Rutman, 1996). Given, Stommel, Collins, King, & Given (1990) examined spousal reactions to the caregiving role. Their findings identified the caregiver responses of negative emotional reactions, feelings of responsibility for the patient, feelings of abandonment by family, and impact of caregiving on daily schedules. Braithwaite (1996), researched the variables of burden and mental health finding that burden experienced by caregivers was related to degeneration of the receiver, conflict, enmeshment, unpreparedness, and unwillingness. Mental health symptoms experienced by caregivers were explained partially by burden but also by stressors such as workload and availability or lack of resources such as self-esteem, physical health and coping mechanisms. The effect of age on burden was a finding in Barusch and Spaids' (1989) research, noting that greater subjective burden was experienced by younger caregivers. Contrary to this finding, they also noted that male caregivers showed lower levels of burden despite often being older, this they attributed to the finding of the action oriented coping styles the men used to resolve problems. Mui and Morrow-Howell (1993) examined sources of strain among senior caregivers (both spouse and sibling). Findings comment on the high prevalence of emotional strain found in both groups, with spouses reporting the highest levels due to the factors of role demand, role conflict, and lack of resources. Strawbridge, Wallhagen, Shema, and Kaplan (1997), compared burden in grandparents, spouses and adult-child caregivers to non-caregivers, all three caregiving groups had poorer mental health with grandparent caregivers experiencing poorer physical health and more activity restrictions. Spouses experienced new demands on their time as well as new problems, "with resulting increases in depressive symptoms and unhappiness" (p.509).Length of time caregiving has also been studied.

Gaynor (1990) studied women as long-term caregivers. She noted that the women who had been caregiving longest experienced poorer physical health, while younger women perceived caregiving to be more psychologically burdensome than the older women did in the study.

Cognitive impairment and its relationship to caregiver burden has generated a plethora of studies describing multiple variables and interventions. Boykin and Winland-Brown (1995), in their phenomenological study, describe the paradoxical struggles of love and frustration experienced by caregivers caring for those with Alzheimer's disease. Similarily, Knop, Bergman- Evans, and Wharton McCabe (1998) examined the variables of marital relationship, coping and depression in caregivers of spouses with Alzheimer's disease, finding that marital relationships were disrupted leading to feelings of guilt, sorrow, anger, resentment, and hostility on the part of caregivers. Molloy, Lever, Bedard, Guyatte, & Butt (1996) studied caregivers of seniors with cognitive impairment. Their findings delineate dysfunctional behavior on the part of the care-receiver as contributing greatly to caregiver burden. Montenko (1989) noted that caregivers of husbands with dementia experienced the most frustrations at the onset of the illness. As well, "women who perceived continuity in marital closeness since the illness had greater gratification than those who perceived change" (p.166). Burden was also found to be higher in caregivers caring for persons with mental impairment, regardless of other physical disabilities in the research done by Browning and Schwirian (1994). "Regardless of the dependant elders' physical diagnoses, the existence of mental impairment had a significant negative effect on caregiver burden overall" (p.19).

Although much information can be gathered from these primarily quantitative studies, what is missing is the important experience of falls and the meaning of that experience both to the person who has fallen and their significant other. This can only be gleaned by using methods appropriate for the qualitative paradigm. By reintegrating part and whole, qualitative studies make us thoughtfully aware "of the consequential in the inconsequential, and the significant in the taken-for-granted" (van Manen, 1984, p.36).

No qualitative or quantitative studies were found specifically addressing spouse caregivers of those with a history of falls. According to researchers in the area of caregiving, it is now time to move forward in research, "in directions that will lead to the discovery of new meanings and uncover fruitful understandings" (Gubrium, 1995). This qualitative study will contributes insights into the kind of relationships in which many senior spouses now find themselves, caring for a partner who has fallen or is at risk for falls.

CHAPTER THREE: APPROACH TO INQUIRY

Introduction

Both gerontological and nursing researchers agree that there is a need to further research in both disciplines through the use of qualitative methods (Trice, 1990; Bowsher, Bramlett, Burnside & Gueldner, 1993; Able and Sanker, 1995; Brandriet, 1993; Luborsky and Rubinstein, 1995; Gubrium, 1995; Bunkers, Petardi, Pilkington & Walls, 1996). The narrative approach combined with interpretive photography was used for this study to understand the experiences of senior caregivers, caring for spouses at risk for falls. In this chapter the following methodological issues are addressed: the methods of inquiry, participant selection, data generation, and discussion of the narrative accounts

Methods of Inquiry

A qualitative study, employing 'Visit' and interpretive photography, explored the experience of caregivers living with and caring for, spouses who have fallen and are therefore at risk for falls. The specific research question was: "What is it like for a senior to live with, and care for, a spouse who is at risk for falls?" Due to the evolving nature of this qualitative inquiry, various sub-questions developed during the visits as a natural progression of the narrational relationship. Questions such as: What are some of the stressors these caregivers experience? What are some ways caregivers use to cope with the stresses of caregiving? Who supports caregivers? What are the gratifications of caregiving?

As the client is the expert in this relationship, questioning and clarification were necessary to fully explain their experience. An integrated methodology of 'Visit' combined with interpretative photography was used to explore the experience of senior caregivers and will be explicated in more detail later in this chapter.

This researcher believes that meaning is both found and created and, for the purposes of this study, meaning was understood as, "the process of reference and connotations, undertaken by individuals, to evoke key symbols, values, and ideas that shape, make coherent, and inform experience" (Luborsky & Rubinstein, 1995). Narrational relationships can be described as conversations in which the intention for the nurse is to aid in the recognition and explication of experiences of certain phenomena to which participants (or clients) have been exposed. This relationship recognizes that any situation is a story, "a humanly constructed set of meanings that make sense out of phenomena" (Gadow, 1994, p.306).

Selection of Participants

The participants for the study were contacted using the control group of a larger research study (n = 200) currently underway in the Calgary area. The purpose of the larger (quantitative) study is to investigate whether, "a comprehensive, standardized approach to the assessment and subsequent development of a client specific care plan for seniors who have fallen, as compared to usual care, will reduce the incidence of subsequent falls and subsequent acute care (inpatient) utilization" (MacDonald & Hogan, 1997). Potential participants for the present study were given an invitation to participate by the research assistants of the larger study. Contact was to be initiated by the participants to request further information, or to volunteer for the study. Eligible participants did not use this avenue of contact, however. It then became necessary to access the control group by different means. One of the principal researchers from the larger study, Frank MacDonald, assisted by phoning several participants in his control group, asking them if he could give their phone number to me regarding this research study. It was by this method of purposeful sampling that I obtained the four caregivers.

Purposeful sampling involves the selection of participants based on the qualities they possess such as "their firsthand experience with a culture, social interaction, or phenomenon of interest (Streubert & Carpenter, 1995). Also known as "sampling for meaning", the goal is to collect elicited narrations describing their experience (Luborsky & Rubinstein, 1995). The collection of participants who were experiencing the phenomena of caregiving for a spouse at risk for falls became my purposeful sample. I then began the conversations that would later become the "Visits". A dialogue was commenced, allowing for the co-creation of their story of their experience. Using 'Visit' as a research method allowed for clear understanding of the experience. In this way the nature of the experience was elicited through their narratives. As Patton (1990, p. 67) explains, "The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth." I was fortunate to have found four such people. The following is a description of the selection criteria used:

Selection Criteria

Using the control group population of the larger study, the following criteria were used for the purposeful selection of the participants. Attempts were made to make the criteria as broad as possible so as not to exclude any couple willing to participate. Consideration was given to the possibility of same sex or common-law partners caring for partners at risk for falls; this is why the first criterion includes “living with”. Participants were selected that would have expert knowledge of living with a spouse or significant other who is at risk for falls. The rationales for each criterion are subsequently given. Each of the participants was to be:

1. Married, or living with a significant other who had experienced at least one fall in the past year.
2. Able to read and converse in English.
3. Willing and able to use a camera.
4. Living in a residential community dwelling in Calgary.
5. 65 years or older.

It was thought that the spouse or significant other needed to have experienced a fall in the past year to help optimize memory and recall. The researcher is fluent in English only, and therefore all written and verbal communications would be in English. To enable the caregivers to express their stories freely and with the least difficulty and amount left open to interpretation, it was felt the participants needed to be fluent in English. Because one of the methods used in the study is photography, the participants needed to be able to use a camera. Not wanting to exclude Mrs. Team from the study due to her visual impairment, her spouse was asked to take pictures of whatever she requested him to. Participants were required to live in the city to minimize the amount of travel time to and from visits. This also helped to keep costs down and allowed the participants to be interviewed in the comfort and safety of their own homes. The age requirement was necessary in order to obtain the senior’s perspective of the caregiving experience.

Number of Participants

Sample size in qualitative studies has been an ongoing area of contention for many disciplines, including nursing (Sandeloski, 1995; Coyne, 1997). Different from quantitative studies where the goal is generalizability, qualitative studies endeavor to explicate meaning or experience. Qualitative studies appropriately use fewer participants to obtain the goal of rich, thick, meaningful descriptions.

Although this researcher believes that meaning valuable to nurses can be discerned from just one individual who has experienced the phenomenon under study, four participants were selected because of their varied experiences in caregiving. As it was initially planned, the study started out with one participant who was quickly joined by another, with the last two participants joining in quick succession approximately two weeks later. The advantage of having the study grow in this way allowed for recruitment of participants as was deemed necessary to further explore the caregiving experience. Four caregivers in total agreed to participate in the study. Of the four participants, two were men and two were women.

It was not my original intention that the care-receiving spouses be present and participating in the visits, as often occurred in this study. When they were present, an effort was made to include them. Different stories emerged for two of the participants (Mrs. Team and Mrs. Reader) when the care recipients were not present. Perhaps different stories would also have emerged from my visits with Mr. Camper had his wife not been present for all of our visits. Having them present contributed to the stories, often supplementing or confirming the words of their spouses.

The repeated visits with each participant, in addition to the two methods of data collection and analysis, as well as the involvement and contributions of family members including the care recipient, helped to obtain the depth necessary to describe the caregivers' experience. The utilization of all of these avenues of data collection makes this study different from other qualitative works employing perhaps a greater number of participants but using only a single method and/or a single interview to generate data.

The first couple I contacted was the Ables. Mrs. Able was the "care recipient" and had experienced one fall with no serious injury, therefore requiring no actual caregiving. Mr. Able, the "caregiver", was willing to talk about his experience after his wife's fall. Because this experience was with one fall only, it was necessary to explore the possibility that the experience might be, or would likely be, different for someone whose spouse had experienced several falls and was at higher risk for falls. For this reason, the Teams, Readers and Campers were recruited to provide this different perspective.

The Teams were the next couple that I interviewed. Mr. Team had experienced two falls, one resulting in a fractured pelvis requiring hospitalization. I called them the "Teams" because they were so much a team in their caregiving. Mr. Team looked after his wife with things she had difficulty with due to her visual impairment, and Mrs. Team cared for her spouse during his times of disability following a fall. Because of this arrangement of caregiving activities, I thought perhaps that the experience might have very different meaning for a senior who provided care to a spouse with more than two falls and no exchange of caregiving duties. The Readers and the Campers were then recruited to further explore this experience.

Both Mrs. Reader and Mr. Camper provided care to a disabled spouse who had experienced several falls and was at high risk for falls as a result. Mrs. Reader provided care to a spouse who had multiple falls but had not required hospitalization. Mr. Reader's other physical ailments increased his fall risk. On the other hand, Mrs. Camper had fallen several times resulting in hospitalization, also for a fractured pelvis. At the time of the visits she was recovering from a fractured wrist suffered in a fall.

Following the repeated visits with all of the participants, it was thought that the caregiving experience had been satisfactorily explored for the purpose of this study and no additional participants were recruited. There were four participants in total. Also participating in the visits were the spouses who had experienced at least one fall and other family members present in the home at the time. These additional participants are listed below.

Mrs. Ables attended the first of the three visits. Mr. Team was present for the first of the two visits. Mr. Reader was present for the first two of the three visits. Mrs. Camper was present for all three visits and their son for the last two of the three visits. The visits ranged from forty-five minutes to two hours and were transcribed verbatim. Each transcript was reviewed with the corresponding audiotape and corrections were made as was necessary.

Because it was the individuals' experiences that were to be explicated from the data, completeness of the individuals' narrative was the desired goal. Rather than using a large number of participants as is required by most quantitative methods to make the study generalizable, this qualitative approach relied on the rich thick descriptions made by the participants. It was anticipated that these descriptions, if true to the participants, might resonate with the reader's own experiences, beliefs, or thoughts surrounding caregiving. Therefore, although the concepts of redundancy and saturation are relevant for determining sample size in other types of qualitative inquiry, the number of visits in this study were expected to, and did, yield the anticipated new and richly developed understanding of the caregiving experience. Many qualitative approaches use only one conversation with participants, or one method of data gathering. The necessary depth of understanding for this study resulted from using two methods of data collection, visits and photography, and the employment of repeated visits over a period of time, which lent both depth and breadth to the study.

Data Generation

A qualitative design blending two relatively new methods, 'Visit' and interpretive photography, was used and will be described below.

Visit

'Visit', as a research method, was developed by Running (1994) and is founded on the belief that "the act of nursing involves the development of a relationship" (Running, 1997, p.117). The author created 'Visit' as a method of inquiry because of her desire for a relational method of research. The method is grounded in Merleau-Ponty's existentialism, Gadow's existential advocacy, and Watson's human caring theory (Running, 1997).

'Visit' was chosen as one of the methods for this qualitative inquiry as it was in keeping with my assumptions and beliefs surrounding the nurse-client relationship. 'Visit' is a method of relational research that requires that descriptions of meaningful life experiences be left intact and not extrapolated to give support to a theme or category. This relational research method was used to develop the unique individual descriptions of the phenomenon of caring for a spouse at risk for falls. The participants were encouraged to share with the researcher their stories about their experiences; this sharing called upon the researcher to reciprocate and, together, a relational narrative was found and created (Bowles, 1994; Boykin & Schoenhofer, 1991; Gadow, 1996). Because 'Visit' is a relational method, Running uses the term 'co-participant' to identify the participants in the study. It is both the researcher and the caregiver who contribute to the creation and evolution of the story. Therefore both the researcher and the caregiver are considered participants, with the caregiver as the expert. Participants will therefore be referred to as co-participants in keeping with the method used for this study. As noted earlier, participants could just as easily have been referred to as co-researchers, as other researchers have done, to signify their depth of involvement in the research process. They are considered to be the experts in this method as only they can describe their own experience.

The process of 'Visit' as a method began with the development of a relationship between the researcher and each individual present at the time, with the main focus on the caregiver. In keeping with the belief that the co-participants are the experts, each was reminded of their expertise at the beginning of the study and of their complete involvement in the research process. This researcher, in stating that the co-participant is the expert, engaged in thoughtful questioning, encouraging an interweaving of clarification and progression as the visits continued and the narrational relationship developed. As anticipated by Running (1997), questions arose from the literature, from the co-participants, the other participants, and from the researcher. Clarification was a necessary part of the research process because the researcher is not the expert. Questioning and clarification are part of the interactional dialogue fundamental to this approach.

Unique to this method is the belief that experiences cannot be separated or analyzed in parts, but must in fact be seen as whole. The lived reality of one person is valued and it is recognized that it may also be familiar to others who have had, or are having similar experiences. "Researchers are charged with reporting the descriptions instead of identifying quotations for the development of essences, casual explanations, categories, themes, metaphors, models, or theories" (Running, 1997, p.119). The experiences, as they are shared and contemplated by both the co-participant and the researcher, are left intact, a woven tapestry of the researcher-participant narration. Techniques such as open-ended questioning and reflective listening were used to facilitate a thorough and rich description of the experience. Each visit was left intact as it progressed. As the visits continued, the story developed building on the knowledge and understanding gleaned from the previous visits. The transcripts were reviewed with the researcher and the co-participant and the photographs revisited. Thus, the presented results were the co-created stories that developed.

Each of the visits was initially anticipated to last between 30 and 90 minutes. Some visits lasted longer than 120 minutes. The visits were audiotaped, transcribed verbatim, and returned to the co-participant at each subsequent visit for validation and clarification. As Running (1997, p. 120) points out, "The researcher [and co-participant are] both involved in the composition, revision, and interpretation of the stories." Running, in her development of 'Visit' as a research method, used a series of weekly interviews taking place over seven months to explore the seniors experience of living in a nursing home. In her study each co-participant was visited at least five times. In contrast, in this study each co-participant except one was visited three times and some four times. The difference in time taken for each study was likely for a variety of reasons. The co-participants in this study were well seniors residing in the community and not in long term care institutions as the participants in Running's study were. Perhaps, therefore, they were able to share their experiences more readily as the possibility of care providers overhearing was not an issue. It was an issue however, that the care receivers in the study would overhear as many attended the visits. Further discussion of this occurs later. Running did not specify how long each of the visits took and perhaps the visits in this study were longer because the co-participants were able to tolerate longer visits than the long-term care residents.

This study began with an initial visit in the co-participants own homes, where details of the study were discussed, and informed consent was obtained. After obtaining written consent, the tape-recorder was started and this became the first visit. This initial visit was followed by a second one, approximately two weeks later. The next visits took place in two to three week intervals as needed for questioning, further clarification and development of the stories, and concluded when the researcher and co-participants determined the stories to be complete. To further add to the depth of exploration of meaning, another method, interpretive photography, was used in conjunction with the visits.

Interpretive Photography

Interpretive photography is a method relatively new to the discipline of nursing. This method is rooted in the belief that symbols "are experiences that can be contemplated, not merely lived" (Nelson, 1996, p.60). In this way it was anticipated that the participants could capture personal meaning on film that symbolized their experience. "The photographic symbol is then used by the research participant to interpret the meaning or experience from a different perspective" (p.61).

The use of photographic interpretation in other disciplines has a long history, particularly in anthropology and ethnology, and recently nursing has begun to see its value as well. Photographic meaning is inherent in the image that is captured, and also in the way the photographer chooses to describe the picture (Gaskins & Forte, 1995; Hagedorn, 1994; Schwartz, 1989; Ziller & Smith, 1977). In the discipline of nursing, Highly (1989) is credited with being the first nurse researcher to use photography (Hagedorn, 1994). Using photographs to research specific situations as they occurred over time in a case study method, Highly took the photos and interpreted them herself. Other uses of photography in nursing research have since followed.

A form of interpretive photography was developed by Nelson (1996) which she labeled 'hermeneutic' photography. Giving each participant a camera, Nelson asked women with breast cancer to take pictures of what they felt symbolized the uncertainty they were feeling as a result of their diagnosis. The photographs were then used in a second interview to help interpret their feelings. In another nursing study, Smith-Percy (1995) gave homeless children cameras, asking them to take pictures of what they found special in their lives over the next 24 hours. Their descriptions of their photos were then analyzed during a second interview with the children. In a phenomenological study done by Gaskins and Forte (1995) photos taken by 12 seniors were used in interviews to identify sources of hope. The seniors were asked to take pictures, over one week, of anything that gave them hope. In a subsequent interview with each senior, the pictures were used to guide the interview process. The interviews were then analyzed as were the photographs and descriptions.

In this study photographic interpretation was used in a similar manner to the studies described above, as a non-verbal method for senior caregivers to explicate their experience. Believing that meaning can be found both in the picture taken as well as the picture not taken, co-participants were asked if there was anything that they hadn't photographed but were thinking about. Equally important to this researcher were not only the photographs and their inherent and described meaning, but also the instances where the individual chose not to capture a particular symbol on film. It was for these reasons that the importance of using this method in conjunction with the visits became clear; the co-participant had the opportunity to discuss why perhaps a certain picture was not taken.

Senior caregivers were given disposable cameras with a built-in flash, along with a letter of explanation of what was required of them. The cameras were given out during the first visit. Co-participants were asked to take pictures (12 exposure maximum), in their own time and at their own accord, of what they felt best captured their experience of living with a spouse who is at risk for falls. Co-participants briefly recorded a note (on the notepads provided) for each picture taken, and the notes were used as a reminder of why that picture was taken. The cameras were collected, the film was developed, and the pictures returned to the co-participants on the following visit. Prior to the photographs being returned, the notes made regarding the photos were examined and discussed if relevant to the visit at it developed. The actual photographs were then used in further discussion of the caregiver's experience. During the visits the caregivers described, for each photo, why they felt each particular picture represented their experience. "The photograph becomes the receptacle from which the individual viewers withdraw meaning" (Schwartz, 1989, p.120). The descriptions were included as part of the visit as it unfolded. The researcher also kept field notes after the visits to record nonverbal communication. Observations made regarding living environment, non-verbal communication conveying mood or gestures were also recorded.

Data Analysis

Chapter Four contains the narrative accounts as co-created with the researcher. They are divided according to the caregiver and then by each visit. In this way the reader can see the progression of the narrational relationship as it developed. 'Visit, as a method, required that the data analysis began immediately, during the first visit. "The participant and the researcher together decide what is necessary in order to create and then tell the story" (Running, 1997, p.120). The analysis occurred continuously during the visits and during review of the transcripts in the following visits. It was in this way that new meanings were generated, really describing the richly textured and multi-layered personal story. Because data analysis occurred continuously throughout the visits, the narrational interpretation that the participants consented to during the last visit was the end result of the research process.

The photographs and notebooks were used as guiding tools within the visits. Following their return to the participants, the photographs were discussed within the context of the visit. Participants referred to them and the notebook descriptions, both aiding in the triggering of important memories and thoughts. The photographs served to add emphasis or level of importance to describing their experience. The content of the pictures became a symbolic representation of their experience. Data analysis of the photographs was interwoven with that of the narrative text as the individual related why a particular picture described their experience. Upon completion of each visit, I listened to the tapes and read along with the transcripts that were transcribed (by a typist) verbatim. I then reviewed the transcripts alone and made notes. On subsequent visits, the transcripts were reviewed at the beginning of the visit, as well as the photography notes the participants recorded or the photos themselves. Each visit revealed new essences describing the meaning the experience had to each individual caregiver. As the visits progressed the narrational relationship developed and the questioning became more pertinent as the researcher began to have a clearer conceptualization of the co-participant's experience.

Chapter Five continues the analysis, but in a more formal way. Different from Running in her 'Visit' method, but similar to photographic methods (Gaskins & Forte, 1995; Hagedorn, 1994; Higgens & Highley, 1986; Smith-Percy, 1995) and other narrative methods (Baker & Diekelmann, 1994; Atkinson, 1997) concepts were identified that the co-participants shared. Each experienced the concept but in a unique way. Chapter Five delineates and discusses these four shared concepts. Salient points are discussed for each caregiver regarding the significance of the spouse's falls to the caregiver, sacrifice of self, marital discord, and supportive relationships. Similar to other narrative and photographic works, this is different from Running's work as she discourages the theming and categorization of the narratives, stating that those are of the world of research not of the world of the participant. Because of the intention of this study to make clear new insights, it is important that salient issues are identified and addressed. This is the focus of Chapter Five, with the addition of pertinent literature.

Credibility

Ensuring credibility is a key issue in the forefront of every researcher's mind. There were many things I did to make the study as credible as possible. These included the repeated visits with each co-participant and the review of the previous transcripts with the co-participant. I also kept journal notes recorded following the visits to remind myself of tone and other nonverbal communications that had occurred. The visits were audiotaped and transcribed verbatim. Following transcription, I performed a "listen to, read through" of the transcripts to ensure accuracy. The transcripts, photographs and descriptions recorded in the notebook were discussed, audiotaped, and so it went on.

Sandelowski (1986) has recommended that the criterion for evaluating qualitative works should be credibility and not validity as in quantitative methodology. Credibility is based on the premise that if a description is true, the participants will recognize it to be their own lived experience. Strategies were employed by the researcher to ensure the accuracy of the description. Because the stories are left intact for this method, and not themed or categorized, credibility is achieved as the stories are true to each co-participant. At the beginning of each visit the transcripts were reviewed allowing the co-participant the opportunity to clarify misunderstandings and make corrections if misinterpretations occurred. The invitation to clarify and question allows the descriptions to remain faithful to the co-participant as their lived experience, thus lending credibility to the data. I was able to further confirm the co-created accounts between Mrs. Reader and myself when I met with her for a "final impressions" wrap-up visit. After reading the stories, she called them "honest" and the connections I had made, "insightful". This added further credibility to the data. As a final way of keeping true to the data, debriefing meetings were held between myself, my research supervisor and the thesis committee member who is also one of the principal researchers in the larger study from which my participants were drawn.

Limitations

The generalizability of this qualitative study is limited to the participants only. Rather, it is hoped that the stories are found credible in that they ring familiar to the reader. This study is also limited by the lack of experience of the researcher. As a novice researcher, I may have unduly influenced the conversation by the questions I asked, by interrupting or speaking a response too quickly. I tried to account for my voice in the story as it unfolded, but may not have done so as clearly as possible in some cases.

Ethical Considerations

Ethical approval was received from the University of Calgary Office of Medical Bioethics prior to data collection. Permission was also received from the investigators of the large Calgary study on falls, to allow access to their control group. The participants all signed consent forms agreeing to the conditions of participation prior to the initial visit. In all cases the spouses acted as witnesses on the consent. Participants were all given a copy of the consent form and were aware that they could withdraw from the study at any time and were under no obligation to participate.

Confidentiality was maintained. The audiotapes and transcripts were coded with only the researcher knowing the true identity of the participants. Access to all of the study materials was limited to my supervisor the typist and myself. All materials will be locked up until they can be destroyed three years after the study has been completed.

At the request of the participants, upon the completion of the project, participants will be given a personal written account of their experiences in a narrative or story form, and a photographic representation of what that experience symbolized to them. Although there is no direct benefit for the participants in the study, participants may find value in the exploration of meaning from out of their experience. "In the telling, stories help... to maintain a sense of identity for by revealing subjective experiences, the person may come to understand ones own life better" (Hirst & McKiel, 1997, p.4). This can be particularly useful to this population as personal identity may be overshadowed by the overwhelming care needs of the spouse. In the search for discovery of meaning, new internal strengths and coping mechanisms are often discovered.

CHAPTER FOUR: THE CAREGIVERS' STORIES

Introduction

In this chapter the stories that developed during the visits are presented. Through the use of photography and narrative, the stories were woven of the caregivers' experience. The co-created thick, rich descriptions of each of the caregivers in the telling of their stories have been left intact to allow the stories to remain true to their tellers. The caregivers have shed light on their experience of caring for spouses who are at risk for falls.

To prepare for the visits I took time to review and reflect on my research question. What was I really asking? During the visits I focused on listening for descriptions of the caregivers' experiences of caring for their spouse at risk for falls. I attempted to put aside all judgements and assumptions not previously delineated. I also reviewed the literature, particularly articles pertaining to story and narratives as well as those describing interpretive photography. I took time to reflect on my assumptions and preconceptions I had so that I might put them aside and focus on reflective listening and questioning. The caregivers' stories are presented in the way they unfolded in terms of time: the Ables were the first couple interviewed, followed by the Teams and the Readers, and finally the Campers.

At the beginning of each visit, a brief description is provided of the environment and surroundings. This was done to enable the reader to better picture the circumstances under which the visits took place. The visits are described, incorporating the co-participant and the researcher's voice. I have included my thoughts or unasked questions to further bring the reader into the setting. Where appropriate, I have also included the emotional tones of the visit to provide further context.

Mr. and Mrs. Ables

"A bit of a warning"

My initial contact with the Ables occurred over the phone. I was given their number by the researcher who had the couple in the control group of his study. He had contacted them to ensure my call was okay and then given me their phone number. On the phone, I told Mr. Ables a little about the study and we arranged a day to meet.

Mr. and Mrs. Ables live in a lovely home in a well-established area. Many amenities are located within walking distance, or by a short drive. Their bi-level home is surrounded by huge mature trees and is nicely decorated in the interior with many of Mrs. Ables' artwork and crafts. Mrs. Ables was born in January of 1932, and Mr. Ables said he is older but did not disclose his exact age.

Visit One

My first visit with the Ables was in early May. When I arrived at the house, I was greeted by a small and friendly dog that took a great interest in me and vocalized his awareness of a stranger in his home. It took a few minutes to get the dog settled before we could begin our conversation. Mrs. Ables was present at this visit and sat beside her husband at the dining room table where we had situated ourselves.

After some small talk and discussion of the contents of the consent form, I spent some time telling them about the study and what I hoped to accomplish by doing it. We then went over the use of the camera and how the photographs would be incorporated into the study. Following this, our conversation was directed to discussing Mrs. Ables' health, her fall, and her current condition. The Ables were very friendly, open and willing to talk about the fall Mrs. Ables had suffered. The Ables explained the fall event and the time leading up to the fall. Fortunately she was not seriously injured but rather bumped, bruised and had lost consciousness briefly.

Although they were willing to talk to me, several times throughout the conversation they wondered how useful their story would be to me because they really didn't feel like their lives had changed or been disrupted much as result of the fall. They openly verbalized that they were concerned what they had to say might not be useful and did not want to waste my time if there were others available "out there" that might have more to tell. I felt like I had to convince them both of the importance of what they had to say and their expertise on the subject. Ensuring that the participant is aware that they are the expert and, that their expertise will be drawn throughout the visits was delineated by Running as part of the method for 'Visit'. I explained to the Ables that what they could tell me would be very valuable, as their situation was unique to the other members in this study because there had only been the one fall, and that many changes or compensations were not made. I was able to convince them of the value of their story as well as their expertise in telling a story about their experience of falling and they agreed to participate in the study. At no time did I feel that their reluctance to participate was for any other reasons then those previously expressed.

We talked for a while longer about any small changes they may have made, as well as anything they might do differently now. For instance I asked whether Mrs. Able still felt comfortable in reaching objects high up on shelves. The kitchen shelves go right to the ceiling and she is not a tall woman. She said that she now left those things for her husband or children to help her with. I noted that they did not have any slip rugs covering their gleaming hard wood floors but rather a large area rug placed out of main traffic areas. Nor were there electrical cords visible or tight spaces of collected furniture, all common causes of falls for seniors. I mentioned these positive aspects of their home layout and questioned whether it had always been like this or were things rearranged after Mrs. Ables' fall. They replied that for the most part things were always like this but that after her fall they did do a check around for potential hazards. They expressed that they were glad the rest of the house was carpeted so that there was less worry about slipping.

We talked a little about their family. I wondered if they had children and how often family get-togethers occurred. I was curious to know if the children lived near by and how much support they might give in terms of tasks and social support. They said they had a son and a daughter who both lived in the city although not in the same district. I was conscious of the time and I didn't want to keep the Ables from other plans they may have had. I closed our conversation and we set up a date to meet again in two weeks.

Visit Two

My second visit took place towards the end of May, two weeks after the first. We sat at the dining room table, but today it was just Mr. Ables and I. I inquired as to where Mrs. Ables was and would she perhaps be joining us later? Mr. Ables explained that she had gone to visit family in Montreal. Both Ables originally lived in Montreal, but had moved west in the fifties. All of Mr. Ables family soon followed, but none of Mrs. Ables' family moved.

We started to talk further about Mrs. Ables' fall. I wanted to hear the story again, but this time from Mr. Ables perspective as he was the subject of the study and during our last visit, Mrs. Ables had told the story. Mr. Ables explained that:

> She had been shopping and was outside, returning to her car when her feet went out from under her and she actually blacked out momentarily as a result of the fall. Luckily there was a young chap driving a half-ton and he helped her to her feet and sat her in the truck beside him until she was feeling better. So she was fortunate that way. Then he asked her if he could take her to the hospital or a doctor or back inside.

Mrs. Ables was feeling better, so she declined the offer and chose instead to return to her car. I wondered later, after re-reading the transcripts, how Mr. Ables felt about her driving home after her incident. Was he upset that she had driven herself home? Did he wish she had seen a doctor? I wished I had explored this further with him. I was very interested to note the amount of detail Mr. Ables presented in his account, despite not actually being there. I wondered if perhaps Mrs. Ables had told the story several times in his presence, or had he gone over the details in his own mind after she had told her story to him?

Perhaps in order to further contextualize the fall event, Mr. Ables then went on to explain that his wife was always cautious about falling since a friend of theirs had fallen. He told the story of an elderly lady in her eighties who went from good health to quite a serious condition:

> She just happened to take a fall at home one time, her legs just collapsed from under her and it turned out she had an osteoporosis problem which she didn't even know about, and she hasn't been the same since. And she (Mrs. Ables) has always been afraid of breaking a hip or something because so often you hear of an elderly person breaking a hip and it's downhill from there, you know.

Now Mr. Ables had verbalized the fear that so many older people have of falling. It sounded to me like a fear both he and his wife shared. Mr. Ables commented that now, for the last two to three years, since this elderly friend fell, Mrs. Ables is very cautious about going for walks and has limited her walking in the winter time. I found this statement interesting because earlier Mr. Ables was so vehement that they really hadn't changed much as a result of the fall but Mrs. Ables now, "seldom walks in the wintertime because of the danger of what might be underfoot". I wondered, was it because it was now warm and dry outside that this limitation did not seem so large? Mr. Ables volunteered that Mrs. Ables had started on a regimen of Calcium tablets (to strengthen and return bone mass) and had a bone density scan (shows health of all bones for mass and density) since her fall. I said that her fall did not appear to have slowed her down too much, to which Mr. Able replied "except that she doesn't go out unless…well at this time of year it's not a problem". In rereading the transcripts and listening again to the tapes, this statement left me to wonder later if at other times of the year it was in fact a problem and what meaning this might have had for him.

Our conversation was beginning to lag a little here so Mr. Ables made the comment, "I guess the idea was for me to come up with ways in which her fall might have affected our lifestyle or something?" Again he reiterated that it hadn't affected their lives except to limit her walking outdoors in the winter. He felt as though it might rob her of some exercise that she should be getting. On the other hand, he felt it made her feel more safe and secure to take the car. He didn't feel that this curtailed her daily activities. He mentioned that she was in an aquatics exercise program that she had given up due to a foot infection but wanted to get back to it at some time in the future. She started the program after her fall. I questioned whether she had started the program as result of the fall to which he confirmed. We talked further about exercise and exercise programs as Mr. Ables looked to be in very good shape and appeared to be on some kind of exercise regime. I questioned him about this and he agreed that he had been going to the gym three times per week for the last twelve or thirteen years. He seemed to be proud of this and of the fact that he was taking no prescription medications.

I questioned him again regarding the layout of the house and any adjustments they had made, as in the last visit we just touched on the subject. He replied that they had made some minor adjustments. He spoke specifically of an aide they had added in the bathroom that fixed on the edge of the tub to assist bathers in and out of the tub. As well they had installed a bar on the wall opposite to the tub and commented that these were things he intended to take pictures of. "That was going to be one of my subjects, one of the few things I can think of." It seemed that because Mr. Ables did not think his life had changed much since Mrs. Ables' fall, he was struggling to find things to photographs. I tried to encourage him in his expressed subject matter. He invited me to view the bathroom set-up in person so it would be easier to relate to it on film. I took him up on his offer. I felt like an intruder into their privacy, but grateful for the opportunity to view an adjustment Mr. Ables stated they had made in their life as a direct result of Mrs. Ables' fall. I wished later that I had further explored the meaning of the new equipment to Mr. Ables, one of the few things we found that had changed as a result of Mrs. Ables' fall:

> And that's about it you know, we haven't had to do much in the way of adapting anything else. Because she is completely mobile, you know. There's no problem that way. I discourage her from trying to lift things that I think she shouldn't. So usually I try to do that end of it myself if I can get to her in time.

We talked further about there being no slip rugs and the carpet running through the rest of the house. He found it to be a plus that the basement stairs were carpeted, as that was where the laundry room was located. Mrs. Ables also kept a studio in which to do her artwork down there. Mr. Ables pointed to a large painting above the TV in the living room that she had painted. He also mentioned her love of other crafts and needlework. We discussed the sedentary nature of this talent, he agreed and expressed hope that this research study might remind her to stay conscious of the need for exercise.

I questioned Mr. Ables about whether the fall had made him more conscious of the possibility of falling himself. He felt that it might have in a very general fashion:

> Over the past few years, I've come to realize that I'm not in my forties anymore and I have to, you know when I'm working around this place, I think twice about how my ladder is placed and things like this. I'm a lot more cautious than I was twenty-five years ago because, well I guess I'm just a little bit wiser too, you know.

We started to talk about their son and daughter. Mr. Ables mentioned that he had been out to his daughter's for supper the night before because he was "batching it". We didn't discuss his family further, as it sounded like his children were caught up in their own lives and that the Ables did not require a lot of support in terms of assistance from either one. Mr. Ables did say that they did enjoy a meal out at their houses at times like this and appreciated the social support that both his son and daughter provided for them.

During our visit, we discussed alternative housing. I felt sure that they would want to stay in their own home as long as possible and verbalized this to Mr. Able who agreed that they'd never discussed living elsewhere. "The very thought of it makes me cringe because we've been living here so long. It isn't a subject that people talk about you know really, until they have to." He said they could likely downsize to a condo, but married for forty-seven years, they had lived in their current home for thirty-seven of those years and couldn't imagine living anywhere else. "The kids don't want us to sell because, as far as they're concerned, this is home even though they don't live here anymore." Mr. Ables spoke to his beliefs about the future by saying:

> Well I think as long as there are, with every couple, as long as neither of them is a real invalid and one of them is in fairly robust health, I think you can always make out in your own home. Because you can always look after your spouse to an extent; although it does get to a point where, in the case of Alzheimer's or whatever, where it becomes not practical. But, I don't know, we've always sort of looked after each other and I would imagine we could manage that up to a point anyway, if one of us took a bit of a turn.

I questioned whether either of them had been really ill in the past and had the experience of having to give care, to which Mr. Ables replied that they had not had to do that on a long-term basis. He said his wife looked after him when he had surgery on a tumor some years ago, but just had to remind him not to do certain things. They had shared caregiving for each other through various illnesses but never for more than a short time. Mr. Ables realized these short care-giving stints were not the same as long-term caregiving and had this to say about what he hoped for their future:

> There's the odd time of maybe she (Mrs. Ables) would get a real bad case of the flu or something and I'd be the nurse-maid for a while or, a couple of months after that, maybe it would be reversed. But that's not the same as on a long-term or permanent basis and I guess we just have to wait and see how we would cope if that ever happened. I suppose it is more correct to say, when it happens because one of these things is bound to right? But as you say, it isn't something you like to think a lot about. But maybe we'll be lucky. Maybe we'll be the lucky ones that don't have it happen.

I thought later about his words and I imagined every aging couple would share his sentiments. I hoped that they would be lucky as I had already met with other couples who were not so lucky. I looked forward to visit three and to seeing his photographs as he gave me his camera containing the three pictures he had taken.

Visit Three

My next visit with Mr. Ables took place in early June, two weeks after our previous visit. Mrs. Ables was again absent. This time I did not question as to her whereabouts. Mr. Ables volunteered later in our visit that she had taken the car to go and do some shopping.

I began our visit by giving him the developed film. Mr. Ables had found a few things to take pictures of. He questioned some of the statements I had made in the picture-taking handout I had given him with his camera. He wondered what I thought would be contributed to the study if he took pictures of photographs, paintings, artwork, or anything. I admired him for really trying to contribute to this study and for his thoughtful inquiry. What did I hope to gain through these other avenues? I explained that some participants might take a picture of a photo of a cabin they hadn't been to due to a spouses falls, or a painting of a favorite area that had not been visited for a while. The three pictures he did take were of the bathroom aides, the bath bar and wall bar. Included here is a photograph of the bath bar.

He said that these aides were really the only things he felt represented his experience, as these aides were concrete evidence that a concern existed. I wondered if they felt more power or control over their situation after the installation of these aides, a sort of symbolic representation of having 'fixed' a problem. Perhaps it gave them the feeling of having done something to avoid another fall, despite her fall having taken place in an uncontrollable environment. Having the aides perhaps gave them a greater sense of security for the present and the future.

Mr. Ables reiterated that since his wife had only the one fall he didn't feel it had put any restrictions on their lifestyle. He again verbalized feeling like he had not contributed much to the study. "I guess the only thing you could really say that has changed is that it's made us more conscious about the danger, of making sure that you don't take a fall". Her fall had given them both a bit of a warning not to take unnecessary chances. Mrs. Ables was capable of continuing an independent lifestyle following her fall, and in doing so, left Mr. Ables able to do the same.

Final Impressions

Contacting Mr. Able by telephone a year later, on July 26, 2000, I discovered that they had been well over the past year and his wife had had no further falls. Stating they were currently in the middle of planning an upcoming family wedding, they suggested we meet in the middle of August. I wanted to get any final impressions he might have. I looked forward to seeing them again.

Mr. and Mrs. Team

"It all falls apart"

Mr. and Mrs. Team live in a newer area of the city in a recently built seniors' apartment complex. The apartments are large and bright and connect to a common area for gatherings. There is a billiard table and well-furbished dining room in the common area as well. The Teams' apartment is situated on the ground level and they have a small patio and grassy area outside the back of the apartment. The interior of the apartment is nicely decorated with petite point pictures and other needlework, as well as paintings on the walls and antique furniture mixed with comfortable chairs and couch. They have no pets. Shopping and other amenities are located near by, but are not easily reached on foot.

I made initial contact in the same way I had with the Ables. Mr. Team answered the phone, but quickly let me talk to Mrs. Team when I requested to. I arranged to meet with Mrs. Team the following week and received their address. I was returned to Mr. Team when I inquired about directions, it was then that Mrs. Team told me that she was legally blind. She felt it best for me to talk to her husband regarding the directions.

Visit One

I first met with the Teams in early June. Both Mr. and Mrs. Team were present in the apartment when I arrived. Mrs. Team greeted me at the door and directed me in to the living room. Despite her visual impairment, she appeared to get around easily within their apartment. After initial introductions and some small talk, Mr. Team retired to the TV room to give Mrs. Team and me a chance to talk. I watched him make his way out of the living room, unsteady on his feet and using the walls for support, and silently admired them both for their courage to be on their own, maintaining this independent lifestyle despite their physical obstacles. This admiration was not to change throughout the time I was privileged to spend with them.

I met with the Teams to discuss the study and what their involvement would entail. I also went through the consent form and the photography involved. Mrs. Team and I together decided that because of Mrs. Teams' visual impairment we would ask her husband to take the pictures of what she asked him to. Mr. Team was, and still is, an avid photographer. I worried that the disposable camera would be too simple and not meet with his approval. I also worried that he might want to take pictures of things she didn't want or ask to be taken, as well that he might not take the pictures she requested him to take. It was a chance I was willing to take as there did not seem to be any other alternatives.

Mrs. Team and I discussed the picture taking further. She stated that they had moved to the apartment complex because of Mr. Teams' falls, and would a photo of the complex constitute what I was looking for? I tried to emphasize, as I had with the Ables, that she was the expert and the pictures would reflect what was meaningful to her in terms of her spouses falls. I agreed that a move to the complex might be meaningful to her as part of caring for a spouse who has had a fall, and that a photo might be taken for that reason. Mrs. Team quickly opened up to me early in our visit, appearing eager to share the past events with someone. We talked about how Mr. Team got around in the apartment. I was interested to know if what I had witnessed was the usual mode. Mrs. Team described:

> Well he follows the walls. He does have a walker and he uses that when he goes out in the hallway. He never goes out without it. But here, when we're in the suite, he doesn't, he just hangs onto the wall or a chair or whatever is handy. He gets up in the night, takes hold of the vanity dresser and walks along between the two beds like a gorilla.

Later, in rereading the transcripts, I wondered at the analogy she used of her spouse walking like a gorilla. Was she upset that he didn't use his cane in the apartment? Or, did something else lead her to make this comparison? She was quick to perhaps temper her earlier statement saying, "But he certainly does very, very well". I wondered later if perhaps she was trying to make amends for her previous comment or was I reading too much into her words? I turned to the tape-recording for assistance to what her comment may have meant, but her tone of voice was neutral and didn't help me further.

Mrs. Team went on to quietly boast about her husbands past achievements. She spoke with obvious pride when she told me he had played many in-door and out-door sports. She quickly brought this happy reminiscence to a close when she began to talk about her husbands' fall. She started out by saying:

> Then of course it all falls apart when you have a fall. He had his first fall nearly two years ago. I had lost my sight so he would take me to the beauty parlor and leave me there and then he'd come back and get me. And this day, he took me to the beauty parlor and I waited and everybody said 'where's that husband of yours? He's never late!' The next thing I knew, our son walked in. Right away I said 'something's happened to your dad.' My son told me not to worry, he said 'he was going to the bank and he had his cane', because he has an artificial knee and he's lost the muscles in his legs, but he was getting along well. But, he tripped and caught his cane in the parking lot and down he went and of course everybody rushed to him and he hates anybody to make a fuss. They called the ambulance in a hurry, so my son came and picked me up.

Later, I wished I had asked how her son came to be notified or was he with her husband at the bank. As she told her story, her eyes misted over with emotion and she reached for a tissue on the side table beside her chair. She took off her dark glasses and I was able to see her eyes for the first time. I felt badly for her sadness and her blindness and uncomfortable that this bad memory had been revisited as it was obviously still painful to recall. Mrs. Team went on to say that she hadn't brought her purse with her to the beauty parlor and didn't have keys to get into their house, so her son had to go to the hospital and get the keys. I didn't ask where she was during all of this; did she stay at the beauty parlor? Why didn't she go to the hospital with her son to get the keys and see her husband? Was she too distraught? She recalled that then her son had to go back and get the car. She went on to say:

> I was a basket case because I do depend on him (Mr. Team). I mean he checks to see if my hair is all right, my shirt is clean and he doesn't like me to be alone. I go out and walk the halls with the help of the railing but he kind of worries about that. 'Don't be gone too long'. So anyway, the hospital sent him home and my son brought him home in his truck. He parked up in the driveway, then he started to get his dad out of the truck. He got him out but then his dad just fainted dead away on the sidewalk. I was just beside myself. We had new neighbors and my son was trying to lay him down and I couldn't get into the neighbors. I really didn't know them and the other side; I went to the next neighbor and asked her for help.... She was so strong. They got him on a chair and took him up four or five stairs to the house. Once they were in the house it was two stairs and a landing, seven stairs and a landing and five stairs and another landing to get him upstairs. I don't know how they ever did it.

Mrs. Team went on to describe further family support she received immediately following her husbands fall. She told me her daughter had come over and described her as a real "tyrant" because she had phoned the doctor to complain about what she felt was her fathers premature release from the hospital. The doctor had not been informed of Mr. Team's admission and was unaware of the X-ray results. Soon after the doctor called back and requested Mr. Team return to the hospital as the X-rays showed his pelvis had sustained two fractures. Mr. Team felt too exhausted to return to the hospital that evening and apparently returned the following day. The night of the fall incident both a son and a daughter and a five-year old grandson stayed overnight to support the Teams in this time of worry and need. Mrs. Team felt the need to call in for further support and called her other daughter, who lived in a small town a few hundred miles away:

> I just couldn't get over myself; it's terrible to think that you can go to pieces like that. But I did. And I phoned my daughter and said, 'just come home, I need you.' So she came home and stayed while he was in the hospital. I don't know how long he was in for. They were teaching him how to walk with a walker. Then he was going to have to climb the steps. Well, he was in such agony I couldn't believe it. We met with the social worker, the doctor, and the physiotherapist at the hospital and we just said, you know, You can't stay in a great big house with all those stairs. Next time you fall you're going to be in a nursing home. And he said he will never go to a nursing home. He said he'll take his own life, and I said 'how are going to do that'? But he got home and he did manage the stairs and he had a walker upstairs and one downstairs.

Mrs. Teams' comments led me to think that she and some of her family may have talked and made some decisions among themselves prior to the multidisciplinary team meeting at the hospital. I assumed that they (Mrs. Team and all or some of her children) believed that the house was no longer safe for the Teams to return to. I wondered who had started the discussion and how the very difficult decision was reached by Mrs. Team to relocate. I believed that because of the concern over further falls at their present residence, and the lack of perceived safety, Mrs. Team felt the need to relocate to prevent further falls by her spouse. I also felt she took Mr. Teams' threat of harming himself very seriously.

Mr. Team found it too painful to sit for his meals on return from the hospital. Mrs. Team said he'd eat standing at the kitchen counter, and she spoke about the tears she shed watching her previously agile husband now in pain and struggling to move.

> So we moved in here, that was in September (the fall incident) and we moved in here in January. He was still on his walker, getting along not too bad. We were surprised he had actually adjusted because we'd had ten rooms and now we're crowded into this little area, but he did. He adjusted and then he decided he didn't need the walker anymore and he walked with his cane. We still had the car and I was nervous about him driving because he didn't have the reflex in his legs. But he's driven all his life practically. Well we didn't go any further than up to the shopping center and back, every time we'd come up with the groceries and he'd take the cart back down to the basement and then come back in the elevator. And I worried every time he went back down. What's happened, will I call the manager and just ask him to go down and check on him and he'd have died (Mr. Team) if I'd ever done it. But that was my biggest concern that he would fall in the basement. Anyway, exactly a year after his first fall, he fell right outside the door to the suite.

Mrs. Team recalled that Mr. Team didn't tell her immediately that he had fallen again. She said she heard him come back into the apartment while she was getting lunch set up. She questioned him as to why he was in the bathroom running the water for such a long time. He admitted to having an 'accident' and that he'd cut himself, "but, he didn't say he'd fallen".

> So anyway, he was going to have lunch and then he wasn't and finally he said, 'I fell' and that's the first he told me. And then he lay on the bed and couldn't move. He wouldn't let me call the doctor. He wouldn't let me phone the manager. He said, 'I'll be fine, I'll be just fine." He lay on the bed

> for three days. I couldn't get his clothes off him. He said, 'don't phone anybody. Don't you tell anybody that I had an accident'.

In rereading the transcripts I was initially taken aback by Mr. Teams words to his wife. Later I began to sympathize with his reluctance to have others know. He was still recuperating from a fall and was perhaps worried about the previous nursing home threat and was concerned what this fall might mean. As well, from what Mrs. Team had previously described, Mr. Team was fiercely independent and did not like to be seen as anything less than capable of looking after him-self and others. Mrs. Team described how she courageously managed care-giving during her spouses time of painful immobility and abided by his wishes to not seek further outside assistance despite her own physical disability:

> He could swing his legs and sit on the side of the bed and I'd put a TV table in front of him, but then he couldn't get back. So, I'd lift his legs and shift him around and had to pull all the bedding off the bed and then put it back on the bed when he got in. You know, everybody said, 'why don't you ask for help? But he wouldn't face that...I could make coffee. I measured it by the cupful you know, in the carafe and I could make toast, but other than that I am useless.

Throughout this visit I was amazed at the courage of this couple. I was also amazed by her physical ability to care so well for him not only because of her blindness but she is small at 5'2" and Mr. Team was 6'2", but has "shrunk" over the years according to Mrs. Team. I responded to Mrs. Team that it sounded like she had done a wonderful job of caring for her husband. She also described how she had managed his bathroom needs and the associated difficulties, I marveled at her inventiveness, and obvious caring. I wondered how she could see herself as useless? She went on to describe, with pride and admiration, the support she received from the three of her four children who live in the city:

> Our children do our grocery shopping for us. They take turns so it's somebody's turn every three weeks and he just phones them a list. Our family has been just wondrous. Even my daughter with her four children; twelve, ten and then the twins that are six. We've got one daughter here and two sons. Yesterday I had to go to a funeral and my son left the office and came and got me and we went to the funeral and he delivered me home again. And I wanted to go see my friend who is sick because she and I were neighbors for twenty years and coffeed every morning and we had our children together. And then we phoned (following the relocation). I would phone her or she would phone me everyday until she took sick. So my son came and got me and took me (to the hospice).

She mentioned that when she arrived at the hospice her son carefully described the surroundings to Mrs. Team so she would 'see' the kind of place her friend was in. I was happy that she had strong network of supports in her children. I was also interested in hearing her talk about her neighbor as she had only spoken about why they relocated and how her husband had adjusted to the relocation. We hadn't discussed what the move meant to her and how she felt she adjusted to it. I questioned her about the meaning of the move to her to which she replied,

> I say this is home. You know I've never looked back. I haven't dreamt about that house and we lived in it for 48 years. I walked in here and this was home all of a sudden. And it's wonderful here.

Mrs. Team spoke to the family support they received in making the move to their new residence. One son recorded the dimension of the suite, and then measured their furniture and was able to tell them what would fit where.

> All the boys took a day off work and they just moved us in. The girls unpacked and put stuff in the kitchen cupboards and that was it. We were

> moved before we knew it and we never looked back. We've been here a year and a half. And as I said, it feels just like home.

Mrs. Team described one example of when she went to live with her daughter for six weeks when her daughter came home with the twins. She felt that the help they were now receiving was a reciprocation of the help she had given to them and the other children in the past. She said it was different for her husband who found accepting others assistance difficult even when it was necessary. "The kids will say, 'well dad, can I help you?' 'I can do it, just leave me alone. I can manage.'

In fact, since his last fall, Mrs. Team said he has taken a role in their complex as a fire captain for the six suites on their corridor. Although Mrs. Team expressed pride in her husbands returning independence I wondered if there was some fear behind her voice as well. She had mentioned that she usually goes out of town to visit their other daughter once every year but that this year she wouldn't go. She said Mr. Team didn't go because they live on an acreage and the ground was rocky and uneven. I wondered later if she was worried about leaving him on his own. Mrs. Team mentioned that her husband had recently been looking at some travel brochures and had asked her if she thought they could go on a train. She told him that she didn't think so, "he's too unsteady."

> He's going on a little bus trip from here in two or three weeks. At least he says he is. But they take a van …and he says he's going to go. He wasn't going to and then all of a sudden he says, 'you know, I think I could do it'. It would just be a circle tour all in one day, you know. I won't go. I'll go up and visit with my daughter or she'll come and get me. I said, 'I'll be fine here by myself.' But I would be fine. I would be fine.

I wondered if she was trying to convince me or herself that she would do alright on her own. She spoke with pride at the accomplishments she had made since losing her eyesight as well as her perceived failures:

> We don't use the dining room downstairs because, well, I don't eat well in public. We get our groceries brought in by our children and he can do quite well in the kitchen, and I can stick a meat pie in the microwave. We buy the tiny carrots that are all packaged and ready to eat. I've made muffins. I had the recipe in my head. And I can make baking powder biscuits, because I can just remember. Oh, I made a stew once but he cut the meat. He was concerned about me cutting the meat. I said no, 'I've got to learn. I've got to be independent.'

The struggle for independence was one she and her husband shared and were apparently very willing to keep fighting for. Both were trying to do what they could to promote their independence individually.

Mrs. Team spoke about other supports she received such as a volunteer from the CNIB who would help her with knitting socks and dishcloths. "I can't sew them up so she comes and sews everything up for me." She also spoke about old ties she had maintained following their relocation.

> From the old neighborhood the odd time, the girls, we used to have a sewing club there and somebody will come and pick me up and take me and bring me back home. Well I've only been three or four times but I say, 'it's such a long way to come' but they say, 'oh no, we miss you so we'll come and get you.' So I really appreciate that. L (Mr. Team) doesn't go out much. Other than socializing with family, he doesn't. He's quite self-conscious. Thank goodness he won't go without that walker.

Our visit drew to a close at that time. I heard fear in her voice as she talked about her husband taking the walker with him wherever he went, I wondered if she was worried that he would only use it for a short time again as he had with his previous fall.

Mr. Team called me that evening. He wondered if they were appropriate participants for the study. He was concerned because he felt himself to be both the caregiver and the person who has had a fall. His comments took me by surprise as I had felt Mrs. Team was also a wonderful caregiver and I wondered if he did not see that. After thoughtful discussion, I reassured him that his wife had the expertise that was needed to describe the care-giving experience as well as she had cared for him following both falls. They were agreeable to continue participating in the study. I made further arrangements to meet Mrs. Team for our second visit.

A week after receiving their camera, Mr. Team called again, this time to inform me that they had taken the pictures and the film was ready to be developed. Picking up their pictures, I had their film developed in preparation for our second visit.

Visit Two

I met with Mrs. Team on our pre-designated day in June, about two weeks after our previous visit. Mrs. Team met me at her door and told me we were on our own for the day as Mr. Team did take the bus trip that we had discussed on the last visit. I commented that I had brought her the pictures and was looking forward to seeing what she had chosen for Mr. Team to take. Mrs. Team replied, "Yea, well he did most of the choosing. He likes to be in charge." I wanted to get her impression of why Mr. Team had called following our last visit and asked her for her thoughts on what she thought he thought his falls had meant to her. She felt that he really didn't think his falls had affected her because:

> He's always been the strong person. He's done every kind of sport you can think of...He's never, well he's always called himself, he was the patriarch of the family.

> When his brother died (at 34), his brother was two years older than he, he (Mr. Team) took over the family. He had two sisters and his mother and everything, he believed he had to look after everybody. We got married and had our first child, then moved to Winnipeg and we came home because my dad had a heart attack. While we were home, his mother fell and broke her hip and right away, we had to move back and look after his mother. He and his brother owned the house his mother lived in. He said 'do you want to move into that house?' I said, "No, I'm not moving into that house.' Well now he doesn't say he's the patriarch, he says he's the taipan because he's been reading these books.

From what she said I thought it was likely he believed he was fully recovered from his falls and back to himself. He perhaps didn't realize the impact his falls had had on her still, even though the outside cuts and bruises had long since healed. I believed that from what Mrs. Team was saying, she didn't mind that he took control of several areas of their life right from the beginning, it was even perhaps an expectation for her that he would. What she did seem to mind was the importance he placed on his family over hers. She appeared to assert herself when she really felt the need, as she did when she refused to move in to her mother-in-laws home. She spoke further about his need to remain independent even when it was assistance offered by his own children:

> I mean he'd do anything for his children but just don't let them try to do anything for him. He doesn't want to be sick and if the boys say to him, 'Dad can I give you a hand?' 'No, I can do it.' I mean we got to the point where we had a young neighbor and he did our snow shoveling for us. But then the lawn, the children would come over and say, 'Dad I'm going to cut the lawn.' 'No you're not. I can do it myself.' And you know, it was pathetic to watch him. That's what the children said you know, 'it's so hard to see Dad. He's trying to push that lawnmower.' And our lot wasn't big because it had a big house on it, but he had to do it. It might take him two days to cut the back lawn. The boys, especially our oldest son, get quite cross with him because he doesn't think anybody can do it and he doesn't want any help. But if he wants help, he doesn't mind phoning them and expecting them to come right away. So you know, I don't know what I can do for him, except when he has fallen, I can carry him in a tray or....

I heard frustration in her voice as she spoke about her difficulty in understanding when giving help was okay or not. She seemed to abdicate her caregiving role and capability to her husband when the fall incident had passed. I wondered if the boundaries for his acceptance of assistance were not well defined. It seemed that in order for Mr. Team to willingly accept help, it had to be at his request on his own terms. I felt that this was probably an area that Mrs. Team was uncertain about, and thought about how difficult caregiving would be under these circumstances. She was capable of helping him but from her comments it seemed that Mr. Team was quick to assert his need for independence and control and to be the caregiver again following his recovery. We talked about the picture with her and two others. Mr. Team had written that they had just returned from getting groceries and his wife was visiting with her son and daughter in law while he put away the groceries.

In discussing the meaning this picture had for her she said, "But you see he puts away the groceries but he has to lean up against the counter. Then he lurches almost. When he first gets up he has to take two or three quick steps to get his balance. And it's the same, he can't put his pants on or his jacket on without leaning against a wall." I was surprised at the meaning she had derived from that picture. I wondered if it stemmed more from the text her husband had written then the photo itself because you could not see the groceries being put away by her husband.

Mrs. Team gave an example of when Mr. Team adamantly declined to continue an independent previous pastime when she spoke about Fathers Day last year. One of their daughters gave Mr. Team a planter for their patio filled with flowers. He told her, "I'm not gardening. I've done all my gardening. You're not going to talk me into it. I've gardened all my life, now I'm not going to do it." I wondered why he was so quick to give up this area of his life that he had previously enjoyed. Did he view the planter as a painful reminder of his previously large well kept yard filled with flowers? Or, was he truly tired of gardening? It surprised Mrs. Team as she thought it would be a small part of something he used to really enjoy, and not too large that it would be a lot of work. She said she had to quiet him down as she could hear her daughter's feelings were being hurt.

Mrs. Team spoke about her friend from CNIB who came to visit and the difficulty Mr. Team had in answering her social queries. I remembered Mrs. Team talking about her husband socializing only with family from our last visit and waited for her interpretation of her friend's visit. Mrs. Team said,

> He doesn't want anybody; he just hates anybody to say 'how are you'. When C, she's the lady that comes as a volunteer for the blind, came last Wednesday, he came to put a blind up or down, I don't know and she said, 'how are you L?' He said, 'Fine, fine, fine.' And she said, 'No, really, how are you?' 'Fine.' And that ends it. He's not going to discuss it.

I wondered if his reluctance to open up to Mrs. Team 's friend was because he didn't want to show any weakness in front of non-family members. In rereading the transcripts later, I was reminded by his previous statements following his falls that he liked to keep things between he and his spouse. Or, if it stemmed from mores learned in the past such as "don't air your dirty laundry".

Mr. Team had taken two photographs of Mrs. Team visiting with C, her CNIB friend. One was of them knitting to which Mrs. Team commented,

> I only knit two things- these dishcloths and bed socks. And I did knit a sweater.... I don't want to knit another one, it was boring. But C, She's at me all the time, 'Now you could do this.' She says, 'You should be able to do everything you did before you lost your sight.' But I can't. I can't read a recipe. "L says, 'What are you doing? Put that stuff away.' And I said, 'I mean it's all I've got; I can't read, I can't watch TV so I've got to have something to do.

Mrs. Team spoke about her frustration trying to knit from verbal instructions read by Mr. Team not knowing what he was talking about and giving up.

Another picture described C and Mrs. Team as "enjoying B's delectable raisin bran muffins." Mrs. Team said she makes them from memory, because she's made them for years. She also said she had recently given away her mix master because she was scared to use it. She worried about catching a spatula or finger in the blades. The meaning that the photographs held to her were things she was doing to contribute to the running of her home despite her disability. Although her spouse had tried to persuade her from many of her previous activities she persevered and the photographs were reminders of the accomplishments.

Mrs. Team spoke about how her husband has been since he has relatively recuperated from his last fall by saying, "he does everything for me. He doesn't really want me to do anything. He'd like to take over the kitchen and I said, you know, I've cooked all my life, it's an area I feel comfortable in. Otherwise I might lose my independence completely." She told me that she had tried to discuss taking some small trips that their complex offers from time to time. Initially he had responded by saying, "No, we would just be in the way." And what was the point of me (Mrs. Team) going, "you can't see anyway". I was taken aback by his bluntness to her and of her seemingly casual recollection of it. I wondered how she felt when he spoke to her that way. She told me that later he changed his mind and started investigating the next outing the complex was taking. She remembered their conversation,

> Well I'm going to go. I guess you're sorry you're not going.' I said, 'No.' 'Well you're not going to stay alone. You can go to C's (a daughters).' I said, 'No, I'm not going to C's, she is busy.' 'Well I'm phoning N (a son) and asking him to come over for lunch.' And I said, 'L (Mr. Team), I don't need anybody, I'm fine. I should have a day to myself and see what I can do.' But you know he has to be in charge. That's it.

I was impressed by her strength to stand up to her husband and by her courage to want to be independent despite his need to be in control. I wondered if this need stemmed primarily out of fear for her safety. I also wondered if Mrs. Team had any concerns about her husband going on this trip in terms of his unsteady gait and potential for further falls. When I questioned her about this she replied that yes, she had been thinking about what would happen if he fell on this trip:

> I say to him, 'Are you taking your walker today?' He'll say, 'No, I'm retiring my walker. I'm ready for a cane.' But he was ready for a cane once before and he fell. Last night I thought you know, he shouldn't go on this trip. What if he falls going through those gardens, he'll be in that hospital. But boy he's come home from the hospital and I'd think how is he going to make all those stairs we had in the other house. And he made up his mind he could do it and he did it. He ate off the counter, he couldn't sit down but he did it. I just hope he gets home safe and sound.

She spoke further about how much he used to go out and that they had only recently given their car away to one of their daughters. I questioned her how it was for them to give up the car as I felt this was probably a meaningful relinquishment of one mode of independence. She replied:

> We had the car until March I guess and he said to me, 'Lets take a trip to Vancouver.' I said, 'Well we're going to fly.' He said, 'No, no, I'm going to drive.' I said, 'L, you're not capable of driving to Vancouver and then on to the ferry.' 'Well we've done it before.' And I said, 'Yea, but I had my sight and you had two good legs.' 'Oh, I could do it.' So a couple of weeks later he said, 'Tell C and B (one daughter and son-in-law) they can have the car. I could still drive. I might buy a van.' And I said, 'We're not buying a van L. If we wanted, the car was only four years old, it didn't have 30,000 kilometers on it and your talking like you're going to buy another car.' He said, 'Well, I've always wanted a van.' I said, 'No way, that's ridiculous.'

She spoke of her increasing concerns about his declining health, saying that his vision was starting to fail and his legs were getting weaker. She worried that he was giving up his walker to use a cane. She knew that he was unable manage curbs with the cane but he found it more acceptable to use when out in public.

I wondered if she had thought about what she would do if something happened to her husband, and questioned her about it. She replied immediately, "I wouldn't stay here I know. I mean I wouldn't need all this room." Then she went on to say that she would never want to live with any of her four children because she didn't want to be a burden to them. She spoke about looking after her husbands mother, "and after that I said I'd never live with my children." My eldest daughter who lives out on the acreage has told me I can go and live with her. But I say,

> 'No, I'm not going to live with anybody.' All I say to L (Mr. Team) is, 'Just leave enough money that I can live some place comfortably. That I don't have to go into a subsidized room someplace.' That's one thing I don't want. I don't want to live with my children and I don't want to have to live in a subsidized room someplace.

Since she had mentioned finances, I questioned whether she kept informed about their bookkeeping. She said her husband tells her when they get a bank statement and how much money is in the bank. She appreciated that he kept her financially informed. He asks her how much money she wants but she says she only spends money on the hairdresser who comes every week. The Teams eldest son had been chosen by them to be their Power of Attorney. "He says if anything happens to Dad, well then he could write a cheque for me." I was somewhat surprised about how organized they were and how savvy their knowledge was. Mrs. Team has obviously thought a lot about this subject.

Throughout our visits thus far, Mrs. Team had not yet discussed the loss of her eyesight and what it had meant for her. I questioned her gently as to how it had happened and could only imagine the magnitude of the adjustment she would have had to make. She had this to say:

> You see my one eye went first and it was crazy, I could knit, I could do everything. But I lay on the couch in the sunroom at home and I'd think, you know, I can only see half of that picture over there or, I can't see the light fixture. What's wrong? But you know I never had any trouble with my eyes…. Finally I said to L, 'I think I'll go, but I'm not going to see the Ophthalmologist. It's crazy to go across town to see him; I'm just going to pick a man out of the phone book that's close to home. So, I went to an optometrist and he tested my eyes and he said 'There's an adjustment in your left eye but your right eye has 20/20 vision.' So he said, 'You need new glasses.'

She said she purchased the new prescription but called the Optometrist a couple of weeks later complaining that she still couldn't see. She described to him that when she looked at a book, the centre of the book was over in the centre of the next page. She went back to see him three times and asked on the third visit if he thought she should see an Ophthalmologist. He told her that it was up to her and reassured her that her prescription was "perfect" and that she needed to get used to it. She asked if she could visit one of the leading eye centres in the city and was told by the Optometrist that they just saw people with cataracts. He did make an appointment for her to see an Ophthalmologist in the same building. Mrs. Team kept her appointment and waited for three hours as the Ophthalmologist was overbooked. She was told she needed a prism and that her focal point was off. There was a mix-up with the information getting back to the Optometrist and then her file was lost and after all that the prism didn't help so they recommended a ground lens. The new lens didn't help either. By this time Mrs. Team was understandably frustrated. She contacted her daughter who worked for the leading eye centre in the city, and asked if they would see her. She was seen very quickly and was told, "You've lost your sight in your eye. You have a little peripheral vision left but not very much. I wonder why they didn't figure that out?" She was then given a graph to look at twice a day and had check-ups done regularly. "In the meantime" Mrs. Team said,

> L had a, well it looked like a pimple on the top of his head. He stuck needles in it and he squeezed and he did everything and the thing kept growing. And it got to be about the size of an egg… He went to our doctor and he said, 'You'll have to see a Dermatologist' Well we aren't going to do that, naturally, eh? So he played around with it for awhile and decided one day, 'Gee it's pretty angry, I'll go into emergency.'

In emergency he was referred back to the Dermatologist. He was taken to the appointment by a son and was told he would need surgery with skin grafting. " And it was that day that my son and I walked out to go back to his car and I said, 'Something's wrong with m then L comes out with his head all bandaged and it was a malignant tumor and he's poking needles in it. But you know, you couldn't tell him."

I wondered what how her husband responded when he was told about her loss of eyesight. I asked Mrs. Team what she had told him when he came home that day. She replied:

> Well of course, the minute I saw him, I was concerned what had happened to him. He said, 'It's alright, it's nothing.' Of course they hadn't even told him that it was malignant. But the minute I heard his voice, I was in tears. He said, ' What's wrong?' I said, 'I'm blind.' And he says, 'Well that's not so bad. I'm not going to throw you away. I can look after you.' I thought, my gosh, everything has happened at once. But then it wasn't three months later that he had the fall at the bank. And it was exactly a year after that he fell outside (the door to their apartment).

I wondered if being "thrown away" had been a concern she'd had. Was this the response she had anticipated? It seemed that Mr. Team viewed it as his gain rather than her loss. He seemed very quick to assume the caregiver role. A role he obviously enjoyed from his past in caring for his mother. The roles soon reversed when three months later he had his first fall.

Mrs. Team revisited the meeting at the hospital following Mr. Team's first fall. It was at this time that they first discussed moving from their home. She described that their decision was encouraged through the presence of their four children, physician, social worker, and home-care nurse.

> They said, 'You just can't live in that house any longer. It's too big and it'd too much responsibility.' And I said to the Doctor ' Do you think he will ever really walk again?' Well he said, 'Well that's up to him.' But, it was up to L what he wanted to do but he couldn't stay in the house. Well of course he, 'Nobody's to tell him.' And I said, 'Well we can't. I mean I can't be

> looking after you and you can't be looking after me. We've got fifteen stairs in this house.'

Mrs. Team talked about the struggle her husband had when he first returned from the hospital and how neither of them were able to view potential new homes. Their children offered to find them a place and the Teams trusted their judgement.

> There wasn't a thing in the North. And our children are all in the North and this was the only place that they could find. They came and they looked at it and they brought their Dad out and he said, 'Well, if I've got to live with five rooms after living in a ten room house, I guess I have to live in five rooms.' I didn't think he'd ever adjust but he has. He's adjusted really well.

I wondered how she had adjusted. The loss of vision and a move to a place she has never and can never see, all within a year. As well as the possible anxieties and fears she had suffered as a result of her husband's fall. Again I was amazed at her courage and obvious resilience.

I asked her again about the pictures her husband had taken for her. I wondered if they were what she wanted or he wanted. I asked her if there was anything she had wanted him to take a photo of that she didn't think he did. She replied that she didn't think he'd taken a photo of the walker and canes at the front door. We reviewed the notepad where each picture was described to see if he had recorded a picture of the walking aides. "I'm sure he wouldn't take a picture of the walker because he doesn't he doesn't want anybody to know he has a walker you know. He wants to be independent too." We weren't able to find one so I offered to take one for her on my camera that I carried in case such an occasion arose where the film had been developed but another photo had come to mind, which it had in her case.

We discussed the canes in the front hall including her white cane. She talked about how her husband wanted her to use her blindness to her advantage:

> He says, 'You should carry your cane know, you'll get a lot of sympathy.' And it doesn't matter who it is, the first thing he says is, 'You know my wife is blind but she's got good hearing.' And I said, 'L, why tell everybody that I'm blind? I don't tell people I'm blind, and I don't tell people he got bad knees. He says, 'Well you are blind. And people are sympathetic, they'll give you a hand.' I said, 'L, I don't want that. I want to be independent.' Well he says, 'You can't be.' Well I said, 'I'll be as independent as I can.' I walk the halls here all by myself and I get along just fine. People open their doors and have a little visit sometimes. I go to the knitting group and somebody always says, 'Do you want me to take you home?' And I say, 'No, I can go home on my own, I just count the doors.' Now I know, I don't even have to count the doors, I just know where I am. But he just has to tell. I don't know if it's sympathy for me or sympathy for him.

I wondered whether he drew attention to her disability to draw attention away from his disability. Mrs. Team thought this might be true. I began to understand, from her statements, that what she did around the house she did not feel was equal to that of her spouse. I wondered if she was encouraged to think that way by her spouse as a way to bolster his need to be the “taipan”. She had related many things she was still able to do, despite her disability, but did not seem to feel them to be worthy. We talked about the picture her spouse had taken of her doing the dishes. She said doing the dishes remained part of her daily routine and that she preferred to wash the dishes by hand as it took so long to fill up the dishwasher. Something she had been able to keep from her old life, before she went blind and lost a significant amount of independence. I couldn’t help but picture doing the dishes with my eyes closed, trying to load them into the dishwasher or wash them by hand, and was again amazed by her will. There were of course things that she did give up, she said, after becoming blind, such as using the garburator. She was afraid to use it and had stopped for safety reasons.

In discussing the photographs and their meaning to her, I felt a tension between what her spouse said regarding her visual loss, and the several pictures he had taken of her doing things she was successful at. Were the pictures taken with pride, or admiration? Perhaps he thought it was something I would be looking for from her, things she “should” take pictures of. I wondered about his choices of pictures he took. How had they come to be taken? I couldn’t ask, as Mr. Team was absent. Mrs. Team alluded at the beginning of the visit that her spouse took what he wanted. I felt that the only picture taken of what Mrs. Team wanted to take was the canes and walker. I was glad I had been able to help her. I realized as we were talking that the photographs weren’t very helpful for her because of her visual impairment. What was more helpful was my reading the description on the notepad recording the photo’s contents. It was after hearing these descriptions that Mrs. Team was able to make comments or continue her story.

We returned to our earlier conversation about her spouse and his activities since his fall. Mrs. Team stated that in the last three months he had taken quite an interest in their complex. Mr. Team was also contemplating a trip to Jasper with his wife next year as part of a tour put on by the complex. She spoke about his involvement with a committee on "Year of the Older Person" as well as with their community centre. She said he also kept busy with his investments, and checking on interest rates. I wondered if she worried about his decisions with investments, she said she tells him, "I don't care what you do in the stock market just as long as there's enough money in a safe place for me when I need it." I could hear in her statement, that financial security was very important to her. She also had made the comment that her husband was ten years older than she was and I assumed she thought he would pass away first.

Throughout my visits with Mrs. Team it was clear that she and her husband relied fairly heavily on their family members to help them. Fortunately they have three children living in the city that are willing to assist them on a regular basis, and more if allowed. For the Teams, help was needed with relocating, and groceries, as well as assistance when one or both parents needed help due to parental hospitalization. I wondered if the Teams would be able to live independently without the support they received from their family members.

Final Impressions

Despite several attempts, I was unable to reach Mrs. Team for a follow-up visit.

Mr. and Mrs. Reader

"On alert"

Mr. and Mrs. Reader live in a small but comfortable bungalow in an older district within the city. A shopping centre with a grocery store and several fast food and moderately priced restaurants are within walking distance, as well as other amenities. I contacted the Readers in the same way I had contacted the other participants; the researcher from the larger study, Frank Macdonald, called ahead and then gave me their phone number once permission was received for me to call. I spoke with Mrs. Reader, and we made arrangements to meet the following week. She then gave me their address and directions to their home.

Visit One

I met with Mrs. Reader on a dark and rainy afternoon in early June. She lived in area I was familiar with. When I arrived, Mrs. Reader asked if I would mind if she let their dog in out of the rain. I told her I was fond of dogs and quickly met another member of the Reader family. Their dog was almost the largest I had ever seen. He actually made their living room appear smaller, especially when he lay down. Mr. Reader was also present, relaxing in what appeared to be a favorite spot by the front window. I noted him to be a slight, frail looking man, wearing oxygen by nasal prongs with a large wheeled walker in front of him. Mrs. Reader was a full-figured woman, appearing in good health.

Mrs. Reader helped me find a chair near a plug for the tape-recorder and then chose what appeared to be a regular sitting area for her. I willingly accepted the hot cup of coffee she graciously offered. Mrs. Reader explained that they had lived at this current residence for ten years. She said they had grown tired of living so close to their neighbors in the trailer park and had wanted to get a dog. She and her husband agreed they were ready for a house. I found this intriguing, as I was aware of people usually decreasing the size and responsibility of a house rather than increasing as they had done at this stage of their lives.

I noted that in several instances Mrs. Reader answered the questions I had directed to her husband, and vise versa. I thought that probably after several years of marriage this might be a common occurrence amongst spouses. I wondered what our conversation would be like if Mr. Reader were not present.

Once we were settled, I explained to the Readers about the research study in order to obtain consent. Immediately they both jumped in with anecdotes they wanted to share. I was pleased with their enthusiasm and willingness to openly share their stories with me. Not wanting to miss anything or not give their thoughts my full attention, I held them off, telling them we needed to talk about the consent and the camera and notebook a little further first. I spent some extra time going through the camera workings and the notebook, and answered similar questions the other participants had asked regarding what the content of the photographs "should be". I explained that anything she thought would help to describe her experience was what she should photograph. She too wondered about her "usefulness" in the study as the other participants had. I was able to reassure her of her expertise and she was interested in continuing as a participant. When I asked her spouse to witness the consent, Mrs. Reader quickly changed our conversation from a discussion of the study to saying, "You can't wait for your husband to come back and attend a thing when they have to be attended to until you learn to do it. Fortunately, I'm able to do it and it isn't a strain so I just take it for granted." I wondered if she was perhaps feeling the strain of caregiving and having to do so much on her own. I wanted to discuss this openly with her but I did not feel comfortable in exploring this further with her husband present in the room.

When I explained that I was looking for an expert's view on falls and what the experience is like for the person that didn't fall and how the fall (or falls) has affected their lives, Mr. Reader quipped, "She just kicks me and says, 'Get up.' Mrs. Reader simply smiled at this comment and said nothing back. I told Mrs. Reader that I wanted her perspective on the impact one spouse's fall has on the other spouse. Her answer began the story:

> Well of course my aspect of it is, why did he fall? I think we have discovered since the initial one, and I wasn't around for it, since then it has been from, hesitancy finding the next place to brace himself. He's using a cane around the house but he uses the cane and walls and furniture to walk and to get up and down. There has been times when he has misjudged the distance that he has to stretch, you know, so that those falls are usually fairly soft.

I questioned whether these "soft falls" had occurred only inside to which Mrs. Reader replied:

> Usually in the house, oh yes, in the house because outside we're both very careful seeing to it that he either has my arm when walking or he has the car to hang onto or the side of the garage or, you know, something like that. A place that's a safe haven.

I wondered how safe Mrs. Reader felt when she took her husband out. How reliable were these safe havens she spoke about? I silently wondered why he did not use a cane or walker outside, as he obviously needed extra assistance. Was he not ready to admit his declining physical health? Were they comfortable with his current level of mobility? Perhaps the changes had occurred so gradually that they were difficult to notice until it was almost dangerous. I asked Mr. Reader how many falls he had suffered. I felt that if he was going to be present in the room for our visit that he should be included in the conversation. He estimated he'd had about seventeen falls in the last ten months. Mrs. Reader began to describe some of the falls her husband had experienced.

She said Mr. Readers' most recent incident occurred when they were visiting at a friend's place. He had come out of the bathroom into a dark hallway and misjudged the distance between walls to hang on to. I wondered about his need to hang onto the walls. Again, why did he not use a cane or a walker? Was it vanity, inconvenience, denial? Mrs. Reader said that this last fall had hurt him as he had fallen against some stairs and suffered some bruises to his ribs and, "gave him a knock on the head." She said there was a strong gentleman present at the house who was able to assist Mr. Reader to his feet and reassure and calm him.

Mrs. Reader went on to describe her husbands first fall. I remembered her saying earlier that she wasn't present for this fall and I was interested to hear her description of the circumstances.

> You know, his head knows what he wants to do but the message doesn't get there. Apparently that was the initial problem when this experience began seriously back in 1995 or1996, I'm not too sure of that date. He was in New Westminster and I was travelling in England with my cousin, he was staying with the other cousin. On this particular day, he went out on the train…and had the sensation of falling backwards he said. Now this is what he was telling me afterwards. And he did fall…. I think he should have gone to the

> hospital at that time. But of course, we're both people who put off going to the hospital or the doctor until it is a crisis. And unfortunately, my not being there, I didn't realize he was having these crises. When my cousin and I got back from England I just noticed that he wasn't as agile as he used to be. He didn't have any difficulty walking.

I wondered why they were vacationing separately. I remembered he'd been retired for twenty-five years and that Mrs. Reader hadn't worked since they were married. I thought perhaps a break from each other was needed, even though she wasn't required to give care to the same degree she is now. I wondered if he had told her about his fall since she hadn't been with him at the time. This question came to mind because one of the other participants was anxious to keep his fall to himself. She said that he had told her. She then expressed sympathy for how it must have felt for her spouse to feel like he was falling backwards and how uncomfortable it must have been for him. She said it was around that time that he started using a cane. Mr. Reader clarified by stating that it was as a result of that fall he started using the cane. He said, "it was a handy way to get around, it was better balance. But in the house I couldn't use it." Mrs. Reader stated that now Mr. Reader has a walker, "but doesn't like to use the walker in the house because the walls are close together and that thing is awkward to get around." I silently questioned Mrs. Readers' use of "that thing" when she referred to the walker; did it upset her in some way? Did she see it as a reminder of her husbands increasing frailty? Was it seen as a cause of frustration?

I noted when I met Mr. Reader that he wore oxygen and that his oxygen tubing was connected to a large machine located in the front hall entranceway. I wondered how he managed to safely maneuver around the cord on the floor as his chair was opposite in the room to the machine, the large dog, and the machine itself, to get down the hall to the bathroom and bedrooms. It didn't surprise me that he was reluctant to use his walker, as it might have seemed to him to be more of hindrance then help.

Mrs. Reader commented that the oxygen was just new within the last week. She described the precipitating incident of her husbands difficulty breathing and the ambulance trip and hospitalization that ensued. She spoke with tears in her eyes about how horrible it was to watch her husband panic in his struggle to get air into his lungs. She described feeling helpless and frustrated, unable to do anything except phone the 911 emergency line. She explained about her investigation of the process to obtain home oxygen and her success in doing so, while her husband was hospitalized. She said it was difficult to get the oxygen initiated as oxygen is considered a medication and therefore needs a doctor's prescription. This, compounded with the holiday weekend, made it that much more difficult. She said that now she is comforted at night to hear the machine running because she knows he's got oxygen.

Mrs. Reader spoke about the increasing restrictions now placed on their activities since her husbands' falls and his new oxygen requirements:

> Before he got onto the oxygen, he used to join a group of men with whom he used to work at the Legion. On two occasions I drove him down there and saw to it that he got into the building... And then I picked him up and brought him home again. I wish that the doctor would say that he could go off the oxygen for two hours a week so that I could take him back to do that because it is so nice for him to get out. And other than that, going to the doctor is the only time he does get out. He finds it very difficult to even manage stairs, so we don't go visit our relatives. Our son is very good at coming and seeing us.

I noted, from her comments that much had changed in their lives recently, from Mr. Reader's newly required oxygen needs to their inability to visit their relatives as a couple. I wondered how this had really affected them, Mrs. Reader in particular. Did she feel the need to keep a close eye on her spouse throughout the day or was she comfortable in leaving him for times to get things done outside their home? I questioned to myself, how much was Mr. Reader still contributing to the running of their household? And how much of a role did their family play in giving them assistance? Mrs. Reader later informed me that Mr. Reader managed their retirement fund, "He is very capable; in fact, very, very capable of handling the investment portfolio. I don't have to worry about that. I just spend the money. He makes it, I spend it… We just hope that it's going to be enough." I knew how valid her concerns regarding finances were. Many seniors have trouble making ends meet for a variety of reasons.

Mr. Readers' decreasing mobility had meant that even finding a family doctor in the city was difficult. Mrs. Reader said that they had moved to the city from the country and their doctor remained in the small town they used to live near. She said their doctor was excellent and knew Mr. Readers' medical history so well and had all of their health records. Mrs. Reader said she wanted to find a "geriatric doctor" here, but said they were waiting until Mr. Reader stabilized a little more before looking.

Mrs. Reader spoke about wanting to find some extra assistance to help her, as her husband was becoming less able to care for himself:

> I understand there are home care people who will come and help and I need to do that. I need to get in touch with them to come and help him do things, you know, have a shower, or even take him for a walk up and down the block. And let somebody else nag instead of his wife.

Mrs. Readers' comments gave me the impression that she was struggling with her husband's increasing care needs. I worried she was quickly becoming burnt out as she felt that she was becoming "a nag". I wondered if she was finding it difficult to motivate and encourage her husband to help care for him-self and get a bit of exercise. I marveled at her courage for having done so much for her spouse. I was amazed that she had struggled without asking for assistance for this long but not surprised, as this behavior is typical of wives as caregivers. She said she realized she needed a break and found it hard to be the "caretaker" all the time. Mr. Reader responded to his wife's comments by saying, "She goes out everyday." With a tired half smile, Mrs. Reader replied, 'I have to do grocery shopping and it does seem, I'm sure to him, that I go out everyday but, it isn't."

Mrs. Reader stated that she hadn't seen her friends for coffee for about six weeks since her husband's latest crisis started. She thought she would resume when her husband's condition stabilized. She said she just needed him to reassure her that he would wear the oxygen when she wasn't around. She sounded frustrated that she was unable to rely on him to be able to leave him for longer periods of time during the day. She worried about him tripping over his oxygen cord and suggested in my presence that he could wind it up through his clothes to enable his hands to be free for walking up and down the halls. He responded to her suggestion with a curt, "I throw it over the chair." There did not seem to be much room left open for discussion. I wondered if this was his usual method of responding to her suggestions. This might make her caregiving tasks more difficult if he was not open to alternative ways of doing things. She remarked that Mr. Reader was on a prescription diuretic, a "water pill" that necessitated him to make frequent trips to the bathroom. I knew that this, in combination with his unsteady gait, put Mr. Reader at an increased risk for falls.

I asked Mrs. Reader if there was anything she did in particular to try and prevent her spouse from falling, she replied:

> As far as the falls are concerned and my reaction to them; it has primarily been when I have been watching, you know. Trying to ensure that he doesn't fall, if it's within my area of assistance that he doesn't. But that has been it, I would say, to be on alert and do what I can, physically.

I was sure there were many things she did unconsciously to prevent falls but they were so much a part of her life they were difficult to pin point. She said she had noticed that if her spouse sat in the chair with his legs bent, for long periods, he was unable to feel his legs when he went to stand up. Mr. Reader commented that his wife had bought him the easy boy recliner chair so that he could put his feet up. I could see that he had several items accessible to him from the chair such as the remote for the TV and books to read. I thought she likely had gathered his commonly needed items so he wouldn't have to get up and search for them. She said that although she does what she can to prevent falls she also wants help him maintain his dignity and foster his independence:

> Most of the time I wait for him to ask me (for assistance) when we're outside because it gives him the dignity of doing what he can as long as he can on his own. If he slows down and he sort of stands there and looks impatient, then I either give him my arm or he says, 'give me your arm.' Not a happy camper. That's hardly surprising. Who wants to grow old like this?

I wondered if was including herself in her last comment. Was she unhappy as well? Did she feel constrained by her spouse's disability? I couldn't ask her in his presence. I would have to wait for my answer. I knew I would learn more during our next visit. We ended our visit at that time and made arrangements for our next meeting. I looked forward with anticipation to her photographs and another chance to talk about the many questions that she left me with.

Visit Two

We met again on our prearranged day about two and a half weeks later. This time the weather had improved and was staying that way. Mr. Reader was again present in his chair, and we resumed the same chairs we had taken for our last visit. After some small talk I asked Mrs. Reader how the photography was going. She responded that she'd taken several pictures for us to discuss. She again asked for clarification about what I wanted in the photographs and I explained they were to reflect the meaning her spouses falls had for her. After I had said this, Mr. Reader responded with, "Well she had to pick me up yesterday, I fell outside the back door."

Mr. Reader's casually spoken admission took me by surprise, particularly when one of the other participants' spouses was very reticent about disclosing his falls. Mrs. Reader commented that she wished she had taken a picture of Mr. Readers walker because, "the day of the fall, he used the walker that evening constantly and, while he didn't walk steadily at least he had it and he could get where he wanted to go without having to rely on me." The meaning for her, she expressed, was that he was still able to manage on his own and his requirements for her assistance did not increase as a result of this fall. I assumed that after Mr. Reader's fall he felt the need to use his walker more than usual because of fear and likely he was sore from his fall earlier that day. Mrs. Reader further explained the incident:

> Yea, it was really, really strange because I never seem to be very far away, except the first time when I was a million miles away, when he does have these falls. I happened to be outside. I heard a sort of thud and then these expletives and spoke to him immediately you know, 'Don't worry, I'm here' and went over.

She interrupted her story to ask her husband if it had helped that she had been there so quickly. He replied that he was glad she had, and was thankful she was able to roll him off of the sore spot. He said that she had trouble picking him up though. Mrs. Reader explained that she had high blood pressure and had been cautioned by her doctor not to lift anything over thirty pounds, and not exert herself. I wondered at the contradiction and confusion she must have felt as she wanted to help her spouse but not injure herself in the process. She and her spouse had also been in an accident previously that had left her with crushed vertebrae in her back, so this left her restricted physically as well. She said," If I do too much, by golly, I pay for it. Anyway, so far I haven't been affected that I know, by his fall yesterday. Just emotionally, that's all."

Mr. Reader described how his wife had placed a stool under his elbow and rolled him so she was able to get under his arm. Mrs. Reader continued:

> Actually, I hoisted him by the back of his trousers. I was aware that it was going to cut into his tummy but it could have been worse. I might have had to have left him there while I went hunting through the neighborhood for somebody to help me, or called 911 which they tell me is acceptable when it's something like that. But you know it always makes me feel like I'm asking for help when I should be looking after it myself physically because up to two years ago I could. So you know, it's difficult to accept my limitations. Yes, it is. I would say his fall and subsequent decline in health has just caused me stress. I wouldn't say my health has declined, I seem to keep going pretty good. But the stress is the difficult part. Sometimes we snap at one another but I guess when you've been married as long as we have, you can survive that.

I knew that falls cause tremendous stress not only on the person who has fallen but on the person attempting to prevent falls as well. I asked Mrs. Reader how she coped with the stress, if there was anything she felt helped. She told me:

> I think a sense of humor is essential. I mean it doesn't work for me everyday, all day, but it does help. And then I have a wonderful support group in young people, my son and daughter who both think I'm marvelous.

I was glad Mrs. Reader had the support of her children, both of whom reside in the city. I wondered if she relied on them for anything else such as assistance with yard work or shopping, a question I wanted to explore with her further later. Mrs. Reader also made reference to activities she liked to do to get away from her multiple demands for a while:

> While he is a 24-hour concern, there are times when I can tune out-going to sleep at night, or in my library reading or attacking letters or something like that. I can put him sort of like on the back burner, him being J (Mr. Reader), while I tend to something else.

Mrs. Reader spoke about how she reads voraciously, "I do a lot of reading. It's all fiction but it's escape literature and I do that a lot." Mr. Reader described his wife's need to read, "She'll go down the hall, she'll be reading a book. You go into the kitchen; she's reading a book." Mrs. Reader continued, "Right, and if I'm going to be in traffic I read at the red lights. I can smile at everybody and read and when the lights turn, fine, put the book down and keep going." I could empathize in part with Mrs. Readers' enjoyment of reading a good story, as I had been the same way in the past. I wondered though if she was using it more for escape then simple enjoyment. Escaping into someone else's troubles could help her forget her stressful reality for a few minutes.

Mr. Reader gave a clue to another stressor in their lives when he commented that their son had recently quit his teaching job within two years of retirement, and that stress had been the reason for his resignation. Mrs. Reader said he was optimistic about obtaining employment and that when he did she would not be so concerned about him. We spoke further about their stressors that Mrs. Reader poignantly described:

> Yes, it's astonishing how much, when you start thinking about it, your life is filled like that. Quiet senior citizenship doesn't seem to enter into our life at all. A certain amount of it is relaxed from when J (Mr. Reader) went to work but he has not been working for twenty-five years.... He retired because of stress, he had a breakdown. It can't be very nice to be like J is when it isn't what you anticipate in your youth. Remember I said that. Enjoy it while you're going through it, while you're living it, remember, this is going to stop or isn't going to be so important, why don't I enjoy it now... Don't wish your life away. I would say that with the exception of last year, it was a fairly enjoyable life. Yes, I would say it was.

I sympathized with the Readers, as it was obvious they felt like their retirement was not what they'd envisioned. Both had to contend with health issues and Mrs. Reader also had caregiving issues to cope with as her husband became increasingly more frail and his mobility unstable. Mrs. Reader talked about her own parents in their later years and the lessons she took away from their experience:

> When my father had to go into a nursing home, she (her mother) didn't know how to cope. She didn't know how to write a cheque. She learned that one quickly. But there were other skills she didn't learn too well and she was a source of problems for J and I. I didn't realize at the time the lesson she was teaching me except that I try to avoid calling on my children to come and help me do things if I can manage at all myself.

Mr. Reader described his experience when his mother-in-law broke her hip, "She fell and broke her hip and she got to the phone and phoned me. I went to move her and she screamed so I called 911. The guy walked in and said, "Yea, typical broken hip." Mrs. Reader continued saying, "And of course this was the first one we had seen. Now I know but not then." She went on to say that her mother had recovered from that fall and had continued to live in her own home for several more years but gradually became frightened of living alone, and became adamant that she wanted to live with them:

> Mind you we just sort of said, 'Do you think you'd like to?' And she said, 'No, she didn't.' So we found a very nice retirement place for her where she felt secure. She wasn't helpless so she didn't have to go into a nursing home; she went into a retirement home. There's a fine bit of difference there. She quite enjoyed the last little while, not having to cook or plan the meals. I'm looking forward to when I can retire.

I wondered when she thought she might be able to "retire", would it be when her husbands' care needs were looked after by somebody else? Or when she went into a retirement home? I wished I had asked her. I wondered if the house was becoming too much for them to cope with as Mr. Readers physical health declined and asked whether they were planning on making a move out of their house in the future or if they had thought at all about it. Mrs. Reader replied that they had thought about moving to a wheelchair accessible bungalow condominium when they no longer have the dog with them.

She had anticipated that her husband would be needing to use a wheelchair in the future and commented that their current dwelling was carpeted and had very narrow hallways that would be difficult to push or wheel a wheelchair down. She remarked, "That's something for the future though. As long as we have this dear friend (nodding to the dog asleep on the floor at her feet), and I'm not saying goodbye to the dear friend until I must. So in the meantime we're coping not too badly." I wondered how much longer she would be able to cope. I was glad they were thinking of their future and making plans. I wondered how Mrs. Reader would cope if her husbands care needs increased much further.

I assumed that as a result of her mother's experience, Mrs. Reader would be involved with the household finances despite that Mr. Reader managed the investments as I had learned from our last visit. Mr. Reader commented that his wife was good at managing the cheque book and Mrs. Reader responded that she had worked for a few years after they were newly married and learned how to handle money and budget from that experience also.

In returning to our earlier conversation, Mrs. Reader described another fall event she witnessed:

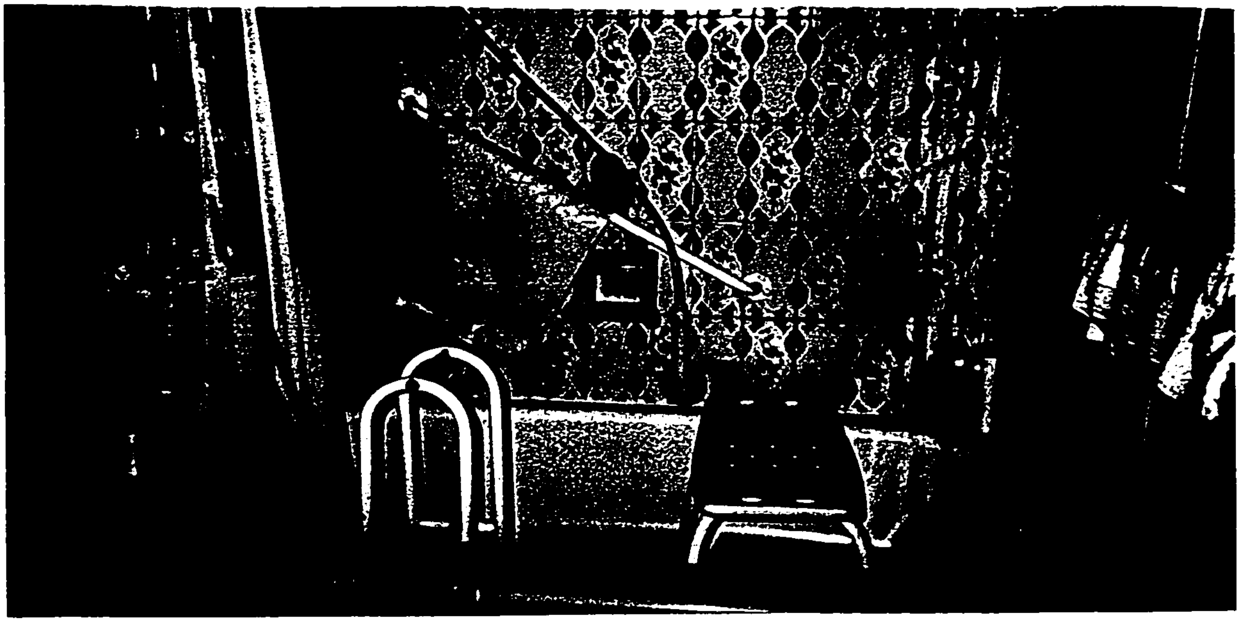
> There was another occasion when he fell. I shouldn't giggle but it was when this began happening, these problems began happening. I guess it would be about a year ago, I was in the kitchen and I heard a thud and I came into the living room. He was prone on the floor... I'm giggling now, it wasn't funny then and it wasn't funny for quite a while after because the problem of getting him back on his feet was something I was new at working out and it was a case of, 'how do we do this?'... Those are the only falls I remember witnessing.'

I was surprised at first about the humor she saw in the event, but then I recognized it as similar to the gallows humor I'd witnessed and contributed in as a nurse in my own practice. Gallows humor is finding things humorous that would not ordinarily be funny. I was sure that it stemmed from realizing now that he was okay and that he wasn't really hurt and that it was after this he really started having problems. I could see her desperate need to find something terrible humorous. Mrs. Reader described the other falls that Mr. Reader had as being onto soft areas such as the chair or bed, or into the car.

Mrs. Reader returned to our previous discussion of ways that she helps her husband stay independent. She commented that Mr. Reader has his own bathroom facilities arranged to help him shower and she is pleased he can still do this with privacy. They had installed conveniently located grab bars so that his bathroom ventures were made as safe as possible. I remarked that Mr. Readers' independence was probably nice for them both, to which she replied, "Well yes, because of what use would I be. I mean sure, I can wash his back." Her comment caught me off guard. I was take aback because she seemed so capable in everything she did; I was surprised that assisting with her husbands bathing was something she felt unprepared for:

> He can wash his own feet with the long thing and copious quantities of towels, which I don't object to how many he uses. The point is that you can do it yourself J. I don't have to go in there and dry you, you can manage that yourself… I don't use that bathroom so he can spread out his shaving tools or whatever other equipment he has, until I can't stand it and I go in and clean up maybe once every few months. It's his premises and I don't go there. My stuff's in the other bathroom.

Mrs. Reader had taken a photograph of her husbands' bathroom.



The meaning it held for her was that he was still able to bathe and groom himself unassisted. This was important to Mrs. Reader, as she was not prepared to assume that into her role at the present time.

Another photograph was of the oxygen tanks located at his bedside and in the hall by the living room.

Again the meaning was reflective of his ability to function on his own, without her assistance. The availability of oxygen allowed Mrs. Reader to sleep comfortably knowing her husband had access to air. She calls it "the comfort machine" because it is a comfort to them both. She still hoped that Mr. Reader would be able to visit his friends at the Legion in the future and described the plan she had formulated of how she would take him and the oxygen tank and leave the tank in the car while he visited. She felt that it was a safety issue to bring the tank inside with him as many of his friends smoked. She also was conscious of his dignity and did not want him to be singled out in the crowd.

She had only spoken about wanting to help her husband continue his social activities but had not yet said what she liked to do. I wondered if she was ever able to get out to do something fun or nice for herself. I asked if she was able to get out of the house regularly. She told me she did grocery shopping once a week and got her hair done every week. She also meets her daughter for lunch about every two weeks. Once a month she sees some old friends for lunch.

I asked her if she was able to keep in touch with old friends and she described two friends that she had been seeing for the last thirty years. One friend remained married and the other was widowed. The three would get together for ballet classes they took for fun and exercise. She said they lost track of each other when the Readers moved out to the country and it wasn't until they moved back that their friendship was renewed. Mrs. Reader explained about one friend whose husband became ill so she wasn't able to visit. Mrs. Reader said, "But I used to phone her and we'd get in touch with one another once in a while. Always at Christmas. So when she got free, that's not very nice but…"

Mrs. Reader was not allowed to finish this intriguing sentence as her husband began talking about the new computer they'd recently purchased. I wanted to ask Mrs. Reader what she meant by her comment "got free". Did she see her friend as locked up because of her husbands' illness? Did she see her own marriage as a jail as well? Did Mr. Reader realize this and that is why he interrupted her? Or, was Mr. Reader hard of hearing or not listening fully to us and did not realize the conversation he was interrupting. Mrs. Reader continued her husbands' discussion about the new computer, never returning to our conversation. I wondered what she would have said if we weren't interrupted.

Now that she had the oxygen tank she could take in the car, I questioned her whether she thought it would allow them to get out more as a couple. Mrs. Reader described the difficulty her spouse experienced when out on errands with her:

> If he wants to come but he doesn't want to come most of the time. Of course, most of the time I go out I'm on personal business. This afternoon I'll be out doing this and that and the other thing so it's sort of like going from one place to another and he can't sit in the car. His other problem is that he's on water pills and he needs a bathroom frequently, often right now! He finds more convenient to stay home.

I thought she probably found easier that way as well. I questioned whether she worried about leaving him. "Not now, no. No not when he's got the oxygen, I don't." She then described the routine she has planned to make sure that his fall risk is minimized while she is away:

> If I think I'm going to be gone for a while, I try to make sure he has the phone by him so that he can get help if he needs it. But no, he's a grown up man. He's not going to do anything silly like try and go down in the basement or something like that. And, when I am gone, oh it's probably a maximum of five hours that I ever really stay out.... I leave him a lunch. For tomorrow I will be gone, possibly at noon and I'll leave a lunch for him and tell him where I am going and what I'm going to be doing so he's relaxed about my being gone. Sometimes when I come home he says, 'Oh, you're back early.' I think, 'Oh, why didn't I stay out longer?' No, I try not to be a worry that way or a concern for him that way. It works both ways.

She spoke about another picture she had thought about taking of the handicapped symbol hanging in the car. She admitted that it helped to make her life easier to have the ability to park as close as possible due to her husbands' unsteadiness:

> I don't use it for myself. I put it in the car when I'm doing the driving but when I'm not, or it happens to be in my car and I'm driving alone, I don't use it. Well, it's not fair. There's nothing wrong with me; I can walk a half block from parking. And probably it's good for me. But no, when I'm with J, he doesn't walk well.

I wondered what the meaning of the symbol was for her in describing her experience. I asked her why she wanted to take a photo of it. She said with tears in her eyes:

> I would like for him to be able to walk as long as he possibly can because it's not going to be good when he can't walk. That's one of the things I try not to think about in the lonely parts of the night.

Mr. Reader was quick to comment; "If I can't walk I may as well die." Mrs. Reader continued:

> Well you see, I don't like his alternative. That's why I don't go there. Because it puts more strain on me because in order to avoid his not having the ability to die, I have to spend twenty-four hours a day watching him as though he were a child. And I don't think that's very nice. 'See you're not being very nice to me either (speaking to her husband).' But on the other hand the alternative is not nice to look forward to either.

When I thought of how she must feel being on call 24 hours a day, it made me realize the enormity of her situation and I was sad to think that her role had changed from that of wife to that of a mother. Her reference to him "not being nice to her either" left me wondering if they had exchanged harsh words earlier that left her thinking he was not nice to her. In spite of her earlier words that they were "coping", I wondered if their marriage was suffering under the weight of his falls, or were there problems in their marriage prior to this? Her next words did not discourage these thoughts as she talked about how role expectations had changed for the better over the years. She felt her husband would be more readily able to cope with declining physical health because:

> He is so accustomed to being looked after. I better change that because modern man, I mean, men that you associate with don't sit and expect to be waited on. Whereas you see this generation and my children's generation expect to be waited on. He (referring to her spouse) takes it for granted. In fact, he's annoyed with me when I don't look after him.

Mr. Reader interceded her comments saying, "I wouldn't say that. I expect you to do certain things." Mrs. Reader continued:

> Yes, which is alright because I expect to do them. But there are times when I get impatient when he asks me to do something and I think, 'Hey, you can do that yourself' But I just think it, I don't say it. Not very often.

Mr. Reader responded saying, "Oh yes you do" Mrs. Reader went on to give an example of her getting her spouse a glass of water right after he had gone through the kitchen himself. He responded that he was worried he would spill it. Mrs. Reader's voice softened as she agreed. The small disagreement had ended. I wondered if these disagreements happened regularly or if they tended to keep their negative thoughts about each other to themselves. Was the stress brought on by Mr. Readers' falls too much for either of them to cope with?

Although Mrs. Reader did not apologize for her earlier comments, I felt she was trying to make amends when she went on to say, "Sometimes I don't think about that when I get impatient with him. I don't think what it's like to be awkward on your feet." She worried about him losing the strength and mobility he still possessed. She felt that any amount of exercise no matter how trivial was better then nothing. I agreed but thought about the fall risks he was taking just leaving his chair. She encouraged him to walk as much as possible up and down their hall, and stairs outside. Her voice had a tinge of quiet desperation when she turned to him and said, "It keeps your upper arms moving and if you lose the strength in your upper arms, you're not going to be able to help yourself up off the floor if you fall again." I realized how hard she was trying to help her husband stay independent as long as possible. I heard in her voice and the comments she had made the difficulty she was having in encouraging him to do what he could to remain independently mobile. I wondered if he was afraid to move around for fear of falling again. It became clearer why Mrs. Reader earlier talked about feeling like a nag, and how she wanted outside help to take her husband for walks.

We ended our lengthy visit at that time. Mrs. Reader offered to show me her extensive library of novels, which I accepted and was duly impressed by. We made arrangements for our third visit and I left, my head swimming with all that I had learned. I was both thankful to the Readers for so openly sharing the depths of their experience with a stranger, and sad for them because of what they were experiencing. I looked forward to our next visit.

Visit Three

At the end of June, about a week and half after our second visit, I met with Mrs. Reader for our third visit. I came armed with photographs and questions but my plans were shaken when Mrs. Reader greeted me at the door. As soon as she answered the door, I could tell something was wrong. I asked if everything was okay to which she responded that Mr. Reader had been admitted to the hospital, three days ago. I immediately thought to myself that he'd fallen and really hurt himself this time. I was thankfully wrong. Mrs. Reader said that due to a combination of a bleeding nose compounded by some medications he was taking, they were unable to stop his nosebleed at home and had gone to the hospital. Mr. Reader was admitted initially for observation and then, because of his poor mobility, was kept in.

I questioned her whether she really felt up to having our visit at this time. I assumed that the last thing she would want to do is have to visit with me about her experience when she had this crisis on her mind. I was surprised when she insisted that I stay. She said she felt that talking to someone might help keep her mind on something else. We went into the kitchen this time instead of our usual spot and sat beside each other at the round kitchen table. I wondered if this was where she liked to sit usually or if perhaps she just wanted to avoid looking at her husbands' empty chair in the corner. After we settled in, she quickly led the direction of our visit talking about the frustration she was feeling about their marriage. She said that since her husbands' nervous breakdown many years ago their marriage had not been the same. Her eyes welled up with tears of sadness:

> I need from him the feeling that he gives a damn about me. One of the things he said to me when I was leaving after visiting him... Sometimes the magic term there is, 'I must go, my meter is running out. I'm going to have to put some more money in it.' Now that may be the magic word, he touched my hand and he said, 'I love you.' and I thought, 'I don't think you know the meaning of the term.' And I don't. Only as long as I am of use to him. You see I am of use to him right now because I am the person who says, 'Okay you can come home.' Love, well I say, since his nervous breakdown, his interpretation of it and mine; mine is, I don't know what mine is. I don't know. I guess I would have to think about it.

Her distress was evident, I knew she was having serious doubts about the state of her marriage. She was faced with options she hadn't been prepared for. She had the power to stop temporarily stop her husband from coming home but was not sure what she should do. She wanted to explain about the changes she had seen in her husband since his nervous breakdown that led to feelings of ambivalence now. I hoped she did not feel like she had to justify her feelings to me. I was not the one living where she was twenty four hours a day. I could only imagine the daily issues she faced.

She told me that since her husband's breakdown he had become very self-centered and impatient with things that he was not involved in. " I used to see glimmers (of his old self). When he first suffered, maybe once in a months time, he would be the jovial person he had been." She felt now as though he barely tolerated her needs and interests. She said they were living in the country when he first had his breakdown and he would go and chop wood for hours at a time to get his mind off things. Mrs. Reader said she went on with things inside and did a lot of knitting. She found it very satisfying to get absorbed in her craft. After a while she noticed he was getting better, "He wasn't retiring into his own self so much but what was coming out was not my friend."

She felt he had changed. She became frustrated with him as he refused the professional counseling his doctor recommended. "He seemed to base his recovery on control. Control of me and of course anybody else that was in the circle that unconsciously realized what he was doing, just removed themselves." She noticed that people began not visiting them as they once had, including their grandchildren. "He didn't seem to realize that it was because it wasn't a pleasant place to come. And to relate that to his unpleasantness, wasn't anything he was prepared to face." She would explain to herself and her spouse that it was because they were far away and it was difficult for people to visit, and often inconvenient as their children began having their own families. "I could explain it to J and then of course at the same time I was explaining it to myself."

I asked if the visits from friends and family picked up when they returned to live in the city. She responded saying that there was always something that needed doing so they were always kept busy and didn't really talk about why family didn't come around very often. "Our son comes to see him weekly and chit chats and our daughter comes to see him very sporadically." Soon after their move Mr. Readers' physical health deteriorated with three heart attacks and a series of blood clots requiring lengthy hospitalizations, providing further distraction from uncomfortable questions.

I asked Mrs. Reader if she felt up to talking to me again about Mr. Readers' first fall. I wanted to hear her tell the story when Mr. Reader was not present. She started by restating what she had told me previously about his feeling like he was falling backwards:

> At that time, that was when he began using the cane because that gave him a feeling of assurance, and he was still looking for the independence of being able to go places on his own… That was when he began experiencing the feeling, now it wasn't continuously, it would happen maybe once every ten days and then he would stay in the house. On this particular day, he fell after having three or four of these feelings, when he was away from the house. Nobody was around to say to him, 'You should go to the hospital.' And he wouldn't take himself to the hospital, no and he wouldn't understand that this feeling was abnormal and should be attended to.

She said that when she got home from five weeks away in England he was recovering well and was seemingly "back to normal". She took him to their doctor, after explaining about his spells he was referred to a neurologist. After several diagnostic tests it was discovered he'd had a stroke resulting in some damage to his brain that impeded the pathways to his knees. Mrs. Reader said she began to notice that since about the last year, he was moving about the house less and less and spending more time in his recliner chair. She said that with a lot of encouragement he agreed to physiotherapy but quit after he found it painful. Mrs. Reader spoke with frustration about his pain and giving up the physiotherapy, " He gave up on the therapy and went back to staggering around from this to that and not wishing to cooperate."

She related a problem she'd had with bursitis and the limited shoulder mobility she experienced as a result. She was angry that her husband had given her little sympathy or assistance then, despite his being physically able. She said he was still employed at that time but wouldn't offer her help. She continued her story:

> There wasn't anything wrong with me. I wasn't bleeding and I wasn't broken so there was nothing wrong with me. Again I didn't assert myself. I didn't say to him adamantly, 'Look, I can't do it.' Which is what I have done this last week and I am having trouble coping with that, as you can see. It is the first time I've ever denied him. I said, 'No, I need help.

I assumed correctly that her husband had been asking her to take him home. Realizing that she could no longer cope with his current needs, she had told him that she needed to get some help in place before he could return. I saw the guilt and confusion she was feeling. She was glad he was in the hospital and felt horrible for feeling that way, but she was so mentally and physically exhausted she needed a break. In discussing this current hospitalization Mrs. Reader said that her spouse was again back in physiotherapy and was currently cooperating with the doctors orders. She said he was cooperating this time because he knew he needed to get back home again.

She then verbalized about the feelings of uncertainty she was experiencing. She had been asked to bring in some day clothes for her husband to wear. She was concerned that this meant they wanted her to take him home. I was able to offer her some reassurance and told her I thought it was likely they wanted him to start dressing in his own clothes during the day. I told her this was a common request and that it allowed for the therapists to assess his abilities for self- care and what equipment needs he might require to aid him. She told me she had spoken with the social worker about the various geriatric rehabilitation programs but said they had not yet assessed him for the programs. She continued saying:

> And if, after that, it was determined that no, he wouldn't be able to come home without a lot of help, then there is long term care. Now when I was talking to this girl this morning (the physiotherapist), she seemed to feel that he could come home after a while, with some more recovery, and with home care help.

I asked her how she felt about her husband returning home. I questioned whether she thought he would continue with the necessary exercise program. She answered that he would if there was somebody else besides her to oversee him. She thought that perhaps with the threat of a nursing home admission hanging over his head he might be more amenable to keeping up his exercises. Mrs. Reader verbalized that she was tired of being the nag and this was something he was going to have to do on his own. "I suppose what I have to do is say, "You do this or you can't come home." Her next words were provocative and I did not have a ready answer when she asked, "When is the line that I draw determined to be no longer fair. And fair meaning him, not necessarily me." I took my time as I carefully considered her unexpected question. I told her that I thought the line should be drawn when she was no longer able to cope with caring for him. Her response did not surprise me. She said it would all be different if she could have her friend back. I felt that she would go to the ends of the earth for the man she married but now that man was gone and now she wondered what her obligation to the man left behind was.

I wondered how their son and daughter were coping with their father's latest hospital admission. Mrs. Reader said that their daughter had seen him daily, "It's a duty and she stays a half hour knowing that that's probably her limit because she resents that fact that, I suppose that I've dissolved." Mrs. Reader explained that she had only seen her daughter "peripherally" since Mr. Readers' admission because she is so busy. Mrs. Reader also thought she might be having some problems in her marriage as well, although they had not discussed it directly. "She probably isn't talking to me about it because she knows I'm overloaded."

She spoke about needing her children for their support at the hospital to help convince her spouse to stay in and get better. "I need to have daughter here (motioning to her right side), son here (motioning to her left side), strengthening my spine and saying, "No, you're not coming home." She said she didn't want to burden her children with her problems but was sure they would support her and help her. She worried that her son had already changed his holiday plans for her, "And it's while I'm talking to you just now, it sort of clicked; well I'll just bet you he's wanting to be around. Not that his father is going to die because we know that he's not." I told her that he was probably wanting to stay close to home in case she needed him. She said she wasn't sure if she wanted that responsibility. She was upset to think that her son had changed his summer plans. I told her I was sure he wouldn't have it any other way. She agreed. Again the uncertainty of what the plans were for her spouse reared up:

> You see if we knew, if we three people, my son, my daughter and myself knew that he was going to have this program (referring to the geriatric rehab program) which was going to advance per se, or according to a schedule or something, we could all relax. But I'm uptight all of the time because I'm going to see him this afternoon with his clothes and I don't know if they're going to make me take him home with me. Up till now I've been relatively safe because he was wearing hospital issue.

It was at this point she dissolved into tears again. As much as I wanted to be able to tell her that she had nothing to worry about, that her husband would stay in the hospital until she was ready, I did not know and could not make her empty promises. All I could say was that I didn't think it would be today and reiterated that clothes are brought in to help with assessment and normalization of the environment.

Mrs. Reader went on to express a deep fear. She asked, "What's to stop him from getting dressed and coming home? And if he does that, what do I do? See the silly places my terrified mind takes me?" I tried to reassure her that the doctors and nurses would do their best to convince not to sign him-self out against medical advice. She said that even when they were talking about him moving to the rehab unit her husband told her, "I'm not moving from here and when I do move from here, it's out." So she said she just dropped the subject:

> I'm not going to defy him until I have a lot of backup. Until I've got this square where somebody says to me, 'Look, when he can do this, then he can go home. If he can't do this, then don't worry, he's not coming home.'

I tried to help her find indicators that he might be able to go home and told her that he should be able to mobilize to the bathroom by himself. To which she replied, "Well he can get to the bathroom by falling from wall to wall." I told her that he should also be able to dress himself and get washed with minimal assistance. She thought he was still able to do those things but she wasn't sure. I asked her what she saw as being the ideal outcome of this experience to which she replied:

> Ideally, all right, I would like to have a man come home like a good companion that is cheerful, that doesn't have to be in control to be cheerful. Let's go back forty years please. So you know it's not possible. So ingrained in being the person that he is, I don't think it's likely to change. But if he is going to have to come home then fine, he comes home, we have people come in and help with his care. I don't like him well enough to make the effort anymore. That's a terrible thing to say.

We talked about how he wasn't the same man anymore. She said she would like to be in love with him again but realized the man she married was not coming back. We talked about making application for long term care for the future and I reminded her that because her husband was still mentally competent that he would need to be involved and agreeable to the application. She said that she was aware as the hospital social worker had told her the same thing. She felt sure he would never agree to the application.

Mrs. Reader redirected our conversation by revisiting our previous discussion regarding the differences in men of her generation compared with men now:

> Men of my generation are really odd. As long as their mother/ wife is there, they're alright. Women are just the opposite. Most of us don't need anything more than ourselves. I mean it is very nice to live with a nice person, in fact it would be wonderful to live with a companion, somebody with whom you can share enjoyment, etc. But we don't have to have it. Isn't that strange? They all say, "Yes, I can do housework, but they don't expect to.

I asked her if she thought she might be able to cope with having him home if she had a lot of home care assistance. She replied, "If I can get emotionally cured. If I can..." She stopped speaking due to her tears at this point. I gently asked her what she thought would help her get well emotionally. She did not know as this was a new experience for her and she was not used to the emotions that she now had to deal with. She said that if they told her that her husband was ready to come home, "I'll run away." Her words were said in such a way that I knew she was just wishfully thinking.

I asked if she and her husband had ever talked about a future time when she might not be able to look after him anymore. She replied:

> No, because he's not prepared to consider it. It's inconceivable to him that I am in emotional knots right now because so far I haven't cried in front of him, just around the corner. I don't know whether that's pride on my part that I don't want him to see me crying. I don't want to give him the satisfaction. I have cried frequently in his presence and not gained anything

> by it. I've tried anger. I've tried giving him back his own words. None of that helps. I guess what I need is a psychiatrist.

I was moved by her struggle. I was glad she had the insight into her emotional turmoil to recognize that she needed someone professional to talk to. I encouraged her to seek out professional assistance. She said, "I guess I need someone to tell me I'm alright." I spoke up that I thought she was doing amazingly well under the circumstances. I also encouraged her to talk about her concerns with her husband so that he would be aware of all of the issues that needed to be addressed prior to his coming home. She replied that she'd tried to be open and honest with him in the past but that he hadn't retained it and had gone back to unpleasant old ways.

Mrs. Readers' dog interrupted us at this point, sensing her emotion he nuzzled her hand. I noted he had not left her side since we sat down. Mrs. Reader commented that she had used the dog as an excuse to leave the hospital on several occasions. She also said that the dog had been therapeutic for her as she could take him on long walks and sort through her thoughts.

Mrs. Reader verbalized that for the first three days of her husband's admission she prayed for them not to send him home. She commented that she was ashamed of herself for doing this. I tried to reassure her that she had nothing to feel ashamed of and that her response was perfectly normal. She was unprepared emotionally to have him home at that time. She said she didn't understand why this was all so hard to cope with. "I'm not used to not being able!" she cried. As a mother she had felt in control and able to deal with any crisis as it arose. She wondered why it was so different now. She interrupted our conversation to let the dog out saying, "Okay I'll let you out, I'd want out too if I could get away from this, we would all run away from this, we would all run away, wouldn't we."

I heard anguish in her voice as she spoke. I wished (not for the first time) I could magically take away her suffering. I told her something that I had learned as a nurse and strongly believed, that she had to care for herself before she could care for anyone else. She wondered if she was trying to help her husband out of love or responsibility. She struggled with this insight saying, "I don't know, it's moment to moment; day to day, I don't know. If the solution is looking after myself and turning my back on J (Mr. Reader) is that going to make me happy?" We talked about why she thought she would be turning her back on her husband in caring for herself. She said it was difficult to think about herself when all these difficult decisions had to be made.

I remembered our previous conversation about her mother going into a retirement home and how Mrs. Reader felt about nursing homes. Things have changed over the years that she may not be aware of from the long term care in her mothers' time I told her what I had seen as a nurse who has visited many of the facilities in the city. We also talked about the planned activities and social opportunities long-term care offers. I was careful in my words to her, as I did not want to influence her decision-making, at the same time I also felt she needed to be informed. I suggested she ask to have a family conference where the physician, multidisciplinary team and family could get together and voice the issues that the Readers were contending with. I know families in my own practice had found these conferences extremely beneficial, and I was sure the Readers would too. I knew there was a lot of community supports in the city, Mrs. Reader just needed assistance in accessing them. I personally knew the team at the hospital where her husband was and knew she was in good hands. She said she felt that even if he came home, it would only be temporarily as she could see his care needs rapidly increasing.

Leaving this subject she directed our conversation back to our previous discussion about her parents' experience. She said she wondered how her mother ever coped with all this. Recalling our previous discussion about her parents, I asked if her mother had had a similar experience to which Mrs. Reader replied:

> Yes, except that she and my dad had a very wonderful relationship. Dad was a brilliant man. He was very loving, very caring. Mother was carried around on a pillow. When Dad had to leave the house, Mom had to learn everything; how to write a cheque, how to look after herself. It was very difficult for her to put him in a nursing home... He got, what do they call that; dementia? Where he would have intervals of not knowing where he was, what time of the day and it was a problem for Mom because he was still physically able to get up and do things. She'd find him outside. That wouldn't be too bad in the summertime but of course in the winter...so their family doctor helped.

Mrs. Reader said that her situation was different because her husband was still mentally aware. She worried he would come back at her verbally. She said her mother never had to worry about her Dad saying to her, "Why have you done this too me?" Something she feared from her own husband.

Another worry she expressed was that her husband might lose control of his bodily functions. She said that they had had some problems travelling due to the water pill he was on and when he needed to go it was immediate. She said she was always a private person and was deeply embarrassed at the male bodily functions. She told me about an incident at the hospital when she was speaking with the social worker:

> He said (the social worker) something about the possibility of J needing diapering. I guess I made a sound or something because he looked around to me and he said, 'Do you think you could cope with that?' and I said, 'No.' It was as firm as I could make it. When I got the opportunity to talk to him one on one I said, 'That's something I simply cannot do.' Even if I could physically do it, I said I'd find it so distasteful.

I tried to reassure her by describing the new incontinence pads I'd seen that were like padded underwear. She felt better because those would be something he could look after himself.

We closed our visit, as she was anxious to get ready to go to the hospital to see what this day was going to bring her. I wished her luck and silently said a prayer for her. I thought she needed all the help she could get.

Final Impressions

"Taking it day by day"

I met again with Mrs. Reader July 19, 2000 a year after our last visit. Mr. Reader was also present in the room, occupying his usual chair. Entering their home, I noted that several things had changed since I was there last. The oxygen machine or, as Mrs. Reader had referred to it many times, 'the comfort machine' in the front hallway had been replaced by a lovely table holding ornaments. There was no oxygen cord trailing across the living room nor was there any sign of the large but very friendly dog. I feared the worst when I inquired as to the whereabouts of their beloved family pet. My fears were confirmed when Mrs. Reader tearfully replied that he had passed away in January. She sounded surprised when she said she still got choked up about it. I could sympathize with her, having a four-legged family member also.

Settling in on their comfortable loveseat, I gave her the previous transcript to read and the photographs she had taken, to review again. I also gave her the notebook she had used to record the pictures in to help refresh her memory. Having thirty pages to read she to settled in her favorite chair and started in on the transcripts. Leaving her to her reading, I struck up a conversation with Mr. Reader. I inquired as to his health, wondering to myself where his oxygen went. It was unusual to not require oxygen when he once had for a permanent lung condition causing bouts of shortness of breath, which he had experienced in the past.

When I asked him he replied, "Got rid of it, don't need it". Looking up from her reading Mrs. Reader asked, "Why is that J, why do you think you don't need it anymore? Do you not get short of breath or are you used to now so that you don't panic anymore?" Mr. Reader replied that he still got short of breath but it didn't bother him like it used to, "Nope, I don't need it". I wondered why he had felt the need to be rid of the oxygen, in previous conversations he had mentioned how he wouldn't have to worry when he couldn't catch his breath now that he had the machine. I wondered how Mrs. Reader was coping with the absence of the "comfort machine" as she used to call it. I remembered how she liked to hear it running at night as it put her mind at ease knowing he would have access to oxygen when he needed it. Mr. Reader commented that now, "I get her to turn on the fan in my face, and that's all I need." I looked to Mrs. Reader for confirmation to which she nodded her head in the affirmative.

There was the distinct smell of fresh cigarette smoke in the air when I had arrived, a smell I had not noticed in my previous visits. I noted a fresh package of cigarettes by Mr. Readers' chair. I told him that I hadn't realized before this that he was a smoker, although his lung condition had sparked the distinct possibility in my mind that he had smoked in the past. Mr. Reader replied that he had been smoking for forty-five years, "nothin else to do here." I asked him if he had quite smoking when he was started on the oxygen, to which he replied that no, he would just take it off during that time, and put it back on when he finished his cigarette.

I noticed too that beside him was not only his walker but his cane, I had seen him moving with his walker extremely slow and unsteady, I couldn't imagine what he used his cane for, I hoped it wasn't for ambulating. Perhaps his denial of the reality of his physical health was worse than I had thought. In fact I was quite surprised that Mr. Reader was home. Given what Mrs. Reader had told me about his refusal to cooperate with physiotherapy in the past, I had doubted he would be safe to go home again. I thought he must have worked very hard to get stronger enabling him to be discharged.

When I asked how he was walking he replied that he wasn't, I had noted the new wheelchair at the front door. Either he had relapsed quickly after his discharge from the rehabilitation program or he hadn't finished the program if his walking was so poor. I worried about this latter possibility, had Mrs. Reader's worst fear come true? Had he left against medical advice? I knew he was capable of doing that but hoped that he hadn't. Unfortunately, this scenario was later confirmed when she began her story of the events as they occurred since we had last spoken. Bringing me up to date, she said that he was in the hospital for several days and was assessed by the geriatric assessment team. He was found to be appropriate for one of the longer-term rehabilitation programs and was transferred to a long- term care centre where the program was housed, with the intention of returning home following his rehabilitation. Mr. Reader became disenchanted with the program after about a month and called their son to come and get him. "He went AMA", she said, meaning that he had left against medical advise, something she had worried he might do at the hospital. I was only a little surprised at this having come to know this man through the eyes of his spouse. I asked Mrs. Reader if she was able to get in some help to assist her. She said that after he came home she aggressively sought assistance from her family physician who ordered a home care assessment and soon following had caregivers in to help her. In the beginning he was just requiring someone to help him get up and washed and dressed in the morning but after Christmas his condition deteriorated requiring assistance in the evening as well.

Another concern that she had verbalized at our last meeting had also come to pass, Mr. Reader had become increasingly incontinent. "In fact", she said, "When our son brought him home he took about four steps up the walk, opened his fly and peed on the grass, just like that, in front of all the neighbors if they were looking." She was very distressed by this but only had a moment to comment on it briefly when Mr. Reader went to the bathroom. She said he now wears "depends", a brand of adult incontinent undergarment, and has tried other incontinent devices. Mr. Reader had mentioned when I first arrived that he had fallen off of the toilet into the bathtub last week, bumping and bruising his head, when he was trying to apply a condom catheter. I was glad he was still trying to care for himself, as I knew this was one area his wife did not want to tread. Mrs. Reader also stated she now gets assistance twice a month with house cleaning and someone comes in once a week to bath Mr. Reader. As well, the worker who gets him up in the morning helps him to sponge bath. They would also change the sheets, or strip the bed for the mattress to dry, as was sometimes needed. Mrs. Reader told me that she is taking her spouse to the urologist next week for some tests to see if his bladder incontinence can be improved at all, perhaps with the addition of medication. I was glad she was investigating it as I knew how much his incontinence disturbed her. I hoped something would be found that he could get help for.

She said she still does the laundry, now usually at least one load per day, "depending on how he manages from overnight", and does all of the cooking. I asked if she was managing to get out at all to which she replied, "I get out usually about twice a week to grocery shop and see my friends and daughter once a week, usually on a shopping day. I just got back from a holiday last week too and J stayed here." I asked whether they had increased help while she was away, wondering to myself how he possibly could have managed. Mr. Reader replied that they stayed with him twenty fours a day and treated him royally even helping him to walk around the house for extra exercises other than his trips to and from the bathroom. I asked how long she had been away, thinking probably a week was all she could manage. "Three weeks!" the Readers said in unison, both excited but for different reasons. She said she thought she would try and get away again in September now that she knows it is possible, she now knew the need for regular respite if she was going to be able to cope successfully with having her spouse at home again.

I asked Mr. Reader if there was a physiotherapist visiting him to help him remain strong. He replied, "A fellow came but he was too tough. He was like a drill sergeant. Shoulders back, chin up, chest out, all the time". He was asked not to come back after one visit. Again, I was not surprised by this, only saddened that he couldn't see the need to persevere to maintain the little strength he had left. I wondered if perhaps he had given up. His disability combined with his long-standing depressive illness, for which he refused counseling but was on an antidepressant for, could rob him of the motivation he needed to keep trying.

I asked Mr. Reader if he had visited the legion now that he was home and didn't have the concerns about his oxygen. He replied that he wasn't going to go there until he could walk in. I was tempted to try and talk him into going now, as I doubted he would get strong enough to reach his goal. On the other hand, I didn't want to discourage him from trying. I asked if he was trying to walk more, Mrs. Reader replied that she thought he was trying harder in the last few days. I wondered why recently he was making more of an effort. What had suddenly motivated him?

During one of our previous visits I had discovered that Mr. Reader, although unable to help with the running of their home in other ways, still did their financial bookkeeping. I inquired if this was still the case. Mr. Reader shook his head to the contrary, "Nope, she does it all now." He sounded depressed and resigned to this. "I made a half a million dollars on the stock market, for what? I can't go out and spend it! What for?" I was sad for the irony of his predicament, living on a limited income for most of his adult life, suddenly wealthy but too ill to enjoy it. I hoped that his new money was somehow assisting his wife to make her life easier. She said that it was because of this money she was able to get away for the time that she did. She said she hoped her spouse wouldn't be too shocked when she showed him the bill for the twenty-four hour care he received for the three weeks she was away. She said they took excellent care of him and it was worth every penny. I could tell that it had given her respite, she had returned to her reality with renewed vigor and understanding. She realized the importance of the respite to her mental if not physical health and was already planning another "get away". I was happy she could afford these holidays, I knew just how much she needed them.

Mrs. Reader finished her perusal of the transcripts I had given her documenting our visits. She said she had found it to be, "an honest account." She felt I had captured our visits accurately and complimented me on what she called my, "keen insights". I appreciated her feed back because, although I had thought it to be an accurate representation, I was only one of the two creators.

In looking at the photographs she had taken previously, she told me several changes had been made and offered to show them to me. Hoping to talk to her alone, I jumped at the opportunity. I told her I what I had noticed, the new wheelchair at the front door, and the missing oxygen tank. She said she wasn't able to get the wheelchair in and out of the trunk of her car so she needed to hire someone to help her on days when he had appointments. I thought to myself how this must even further limit the already limited outings he now could do. She said she had hired a caregiver to look after him for two upcoming weddings they were attending. "A nice strong fellow, who J likes, to get him in and out of the car and help him go to the bathroom, you know, and help with the wheelchair." She said he was coming to help her next week with Mr. Readers doctors appointment. I wondered how families managed that couldn't afford private care like this. How would they get someone like Mr. Reader to the doctor? My thought was they couldn't.

Mrs. Reader took me down the hall, she showed me the bed assist now attached to Mr. Readers bed to help him get in and out. I noticed that of course the bedside oxygen was missing. She pointed to the ensuite bathroom stating that he couldn't get in and out of it anymore so no one used it. Whispering under her breath, she told me that it had devastated her when he urinated outside their home on his return from the rehabilitation hospital. She couldn't believe he had done that. She said, "I despise him for that." I think that his behavior that day, although I am sure he couldn't help it, was the clincher to force her to make respite arrangements, to help her cope with having him home again.

How much longer could she keep him at home I wondered. I asked her how she was coping with having him home again to which she replied, "one day at a time. I have to take it one day at a time." I left them then. As I was going out the door Mrs. Reader stopped me saying, "Oh, one other thing I forgot to mention, J has had to give up his driving license. We sold his car so now we just have mine." I wasn't aware previous to this that he had retained his license. The thought of him driving made me cringe as his identified problem causing his falls, the disruption of the messages from his brain to his legs, would obviously impair his ability to drive safely. Although I was sad for Mr. Reader I was glad that he no longer would drive. I wished her well, crossing my fingers for her as I had done in the past. Driving home I shook my head in wonderment at the struggles she and others like her were facing on a daily basis. I knew that most people had no idea the struggles many seniors face such as these. I hoped that this study could improve awareness of the heroic seniors I had come to know.

Mr. and Mrs. Camper

"Tied down"

Mr. and Mrs. Camper reside in an older but well-kept bungalow on a busy street. Shopping is located within a short drive or moderate walk. Although they don't have any pets of their own, they look after their daughter's two lively little dogs.

I contacted the Campers in the same way I had the three other couples. I spoke first with Mrs. Camper, after I described who I was and why I was calling, she put me through to her husband, first warning me that he was hard of hearing and had a difficult time with hearing conversations on the phone. I thought that rather than trying to explain about the study on the phone it would be more appropriate to meet with them in person, explain about the study and then see if they were still interested. I set up a date with Mr. Camper after we had both consulted our calendars. I could hear he and his wife discussing various appointments scheduled, trying to find a time to fit me in. I was glad my schedule was reasonably flexible. We were able to agree on a time and I looked forward to meeting them.

Visit One

I set out for my meeting with Mr. Campers with my fingers crossed, hoping that it would turn into my first visit should he agree to participate in the study.

Their house was situated quite far back from the busy road, on a steep terraced hill. Climbing the stairs up the hill I wondered who had the difficult job of caring for the lawn, it looked very strenuous to mow. I rang the front door bell and after what seemed like a long time, a woman answered. She peeked out through the chain, after I explained who I was, she directed me to the side door around the corner. I wondered if I had the wrong day or if they perhaps had forgotten I was coming, as she appeared not to be expecting me. As I followed her instructions I wondered if perhaps I'd gotten the wrong house. I passed through a walkway beside heavily laden flowerbeds thick with the scent of the large peonies and delphiniums planted there. I found the side door and waited for what I hoped was Mrs. Camper, to work through the several locks. I later discovered that Mr. Camper was outside working and hadn't realized I had arrived.

After letting me in, she introduced me to the two dogs that helped greet me. Little fluffy bundles of energy, the dogs sniffed and barked until they were satisfied I was not a threat. I followed Mrs. Camper slowly up the few stairs from the side door into the kitchen. As she moved I realized why it had taken so long for her to answer the door. I wished I had known to go to the side, as it would have saved her a long and painful trip. She helped me to settle into a chair near a plug in the kitchen. She settled herself back into her spot at the round kitchen table. Mr. Camper pulled up a chair when he arrived in from outside. It took a few minutes for the dogs to settle down with this stranger in their midst, but soon all was calm again. I realized that Mrs. Camper was going to stay for this visit and I sought to include her in our conversation. I noted she had a cast on her right arm extending from her hand to her elbow, and that she used a wheeled walker which she sat in front of her, I also noted the deformities in her fingers and hands indicating severe rheumatoid arthritis. I thought to myself no wonder it had taken so long for her to answer the door, she was crippled with a very debilitating and painful disease. She was a small women made smaller by the kyphosis in her spine. Mr. Camper was a tall man appearing in good physical health, with no noted health issues aside from his hearing impairment for which he wears a hearing aide.

I began our visit by telling them a bit about the study and what their involvement would entail. Mr. Camper several times voiced that he wanted to get to the root of his wife's falls and in doing so perhaps stop them. He said that if this study would help them discover why she was falling then he would gladly participate. I helped him to understand that this study would not likely help his wife in the way he had indicated. I told him that this was for purely selfish reasons at this point, but hopefully the study would be used at a later time to help other seniors experiencing similar situations. I emphasized that it would not be beneficial to them in terms of exploring or finding ways to discover why his wife was falling or how to prevent further falls from occurring. I explained about the visits and the photography, and his expertise in describing the meaning of his experience. Mr. Camper, despite the study not meeting his stated needs, agreed to participate. Signing the consent, he verbalized his anger with the health care system in not finding out the root cause behind his wife's falls or dizzy spells. The frustration he was experiencing and expressing was palpable. His wife simply nodded in agreement, appearing to have heard him voice these concerns before.

After obtaining his signed consent, I showed Mr. Camper how to operate the simple disposable camera and the built in flash. I also gave him a notebook to record his photographs in. We talked about the expectations for the photos in reflecting the meaning of his experience in living with and caring for a spouse who falls. Because his wife had experienced several falls, I wondered if his responses would be more pronounced compared with the participants whose spouses had only one or two falls. Or, was it not just the number of falls that make the difference when looking at the ability to cope with caring for a spouse who falls. I thought perhaps severity of the fall(s) and stress levels and support systems also would make a difference to the caregiver. I looked forward to hearing his story of his experience and I was glad he was willing to share it with me. I was once again amazed by the kindness and generosity afforded me by all of the participants.

Mrs. Camper began the story by stating that she had been having dizzy spells for a while and that they, in combination with her arthritis in her knees, had caused her to fall several times. Most recently she had fallen sustaining a fractured wrist on her dominant arm. She said that she had put it out reflexively to stop her fall. She also stated that her bones were made more fragile because of taking the Prednisone (a steroid for helping reduce the inflammation round her joints) she requires for her arthritis. Mr. Camper continued, explaining that because of her falls and these dizzy spells, he feels uncomfortable going out of the house and leaving his wife alone even for a few minutes in their own yard. He said that as a result he stays inside until she is settled somewhere safe for a while and she doesn't need to move.

He expressed that he is not used to being at home and inside so much. Dressed in jeans and a work shirt, cap in hand, I could tell that Mr. Camper was more at home in the outdoors and I thought he must feel constrained or even claustrophobic by his close surroundings. He talked about his previous job as a driver for a large company in the city, and his friends that he worked with. He said he was used to being out and about and was feeling very house-bound since his retirement and more so more recently with his wife's declining physical health.

As he talked, the depth and intensity of the frustration he shared with me in his wife presence startled me. During our discussion I glanced at his wife's' face from time to time trying to gage the effect his words had on her. Was she hurt by his words? She didn't appear to be. Although some of Mr. Camper's words could be interpreted by his wife as blaming or hurtful, she was perhaps secure in her illness to realize that this was not something she caused or anything she could have prevented. The discussion gave me the impression that this was not the first time she had heard him so honestly express these issues.

The dogs began to dance around our legs providing a distraction in our conversation. We talked about them as they entertained us. The Campers look after the dogs for their two daughters while they are at work. They briefly touched on how their one daughter provided them with her assistance almost daily. I was torn, wanting to learn more but respecting that they hadn't been prepared time-wise, for this to be an actual visit. We agreed upon a day when I could return and continue our discussion. I left, pleased that Mr. Camper had agreed to participate, anxious to return and talk to him further.

Visit Two

I met again with the Campers on our prearranged day almost two weeks after our first meeting. This time their son who was in town visiting from out of province joined the three of us. Mrs. Camper and I sat in the same spots we had last time, as did Mr. Camper, their son stood for most of our visit, helping to tidy the kitchen and get some chores done. I wondered what kind of visit we would have with these extra two voices adding to the story. Since there did not seem to be any alternative I decided to relax and see where the conversation led. I revisited the transcript from our previous visit so that their son would know what we had talked about the last time we met.

After a little small talk, I again emphasized with Mr. Camper his expertise in sharing his experience as a caregiver to his spouse. I hoped that this emphasis might help his wife and son understand that although what they had to say was important and valuable, it was Mr. Campers' experience that was the purpose for the visit. I asked Mr. Camper how the photography was going and if he'd had a chance to take any pictures yet. He said that he had taken a few including one or two today, and had kept track of them using the notebook he had been provided. I told him I would get the roll developed so that we could discuss them in more detail during our next visit. We discussed that if he discovered anything he wished he had included on the roll he could write it down and we could talk about it anyway. There were many questions I had and issues I wanted to explore with him. I hoped I could get my answers with the presence of his wife and son.

Wanting to know more about his wife's fall history, I asked Mr. Camper to tell me more about the past incidents. During our last visit he had mentioned that she had experienced six "bad" falls within the last year. I assumed they were noted as being "bad" as she suffered some injury as a result. I later discovered my assumption to be correct as she had suffered some serious injuries with past falls even requiring hospitalization for a fractured pelvis after one fall. Mrs. Camper agreed that she'd had at least that many falls and verbalized that she had experienced many more "little ones" over the last six months.

She said she'd been having the dizzy spells off and on over the last two years, but was unable to find out was causing them. I was intrigued that it had only been recently that she'd begun falling with her dizzy spells. I wondered what had changed, had she started on a new medication for instance or, had one fall simply led to others, as the fall cycle describes. In the fall cycle, a fall is followed by a period of disability when it is easy to have another fall, followed by another.

Mrs. Camper explained that she had also suffered a stroke in autumn two years ago resulting in three hospital admissions. Ben, their son (not his real name) admonished, "Well the last time you were in the hospital, I didn't know because we were on a road trip. I didn't know until a couple of years later." Ben said that his job involves a lot of travel for ten months of the year. He said he returns home twice a year, summer and Christmas, to visit and help his parents. Recognizing the amount of work his sister offered his parents in assistance, he also tried at these times to give her a break. After discussing Ben's job I refocused our conversation on Mr. Campers employment prior to his retirement.

Mr. Camper explained that he had been a driver for a major department store chain and delivered items within the city. He had worked for the company for many years before retiring approximately ten years ago. He said he still associated with the friends he had made while he was still working. "We still go for breakfast, a few of us every second Thursday... There's about six or eight of us. We just get together and have a breakfast and a bull-shit session, if you want to call it that, you know." I asked if he was still able to attend those breakfast since his wife began falling, he had mentioned during our last visit that he was afraid to leave the house in case she fell. He replied that he had a deal worked out with his wife that allowed him to go. He further explained:

> She promises she won't get up until I come home and that's around 11:00. But it sure ties you down; I'll tell you. There's a lot of things I can't get done, like the yard. I got so much work out there I don't even know where to start. And, as I say, I get up every morning at 7:30 and I have my breakfast and I'm all finished by 8:00, you know. Then I gotta wait until D (his wife) gets up and she doesn't get up sometimes until 9:00 or 9:30, sometimes 10:00. Well I could be doing a lot of things but two hours is gone right there, eh?

I was somewhat surprised that he spoke so freely in front of his wife. I watched her face but her expression didn't change and she didn't seem to be hurt by his remarks. Was he so afraid of her falling that he couldn't even go outside? I asked him if he felt the need to be inside so he could hear her if she needed help. "Yea, so, I don't know, I don't know what the answer is but I just wish they could find the... you know, you'd think with all the technology and everything they've got the could… you know what I mean?" I thought I did. I heard his unspoken words, and felt his anguish. He went on, "Well that's what I say. If she didn't have the dizzy spells and she was mobile, then I could get on with a lot of my… a lot of it is outside work and everything else too, you know?" Mr. Camper again repeated the issue at the forefront of his mind; "If they could only find why you're getting these dizzy spells then it would be a lot easier on all of us I think. It would be a lot easier on a lot of people really." I felt badly that Mrs. Camper might think she was at fault in all, or inconveniencing people because of her ailments so I changed the subject. I realized later in re-reading the transcripts that I was uncomfortable with the way our conversation was unfolding in front of his wife. Had she not been present with us I think we would have continued our discussion. I wished I had explored his last comment about "making life easier", more fully.

Mr. Camper spoke up that he couldn't believe that they hadn't found some way to figure out why his wife kept falling. I told him I remembered the frustration he'd voiced during our last visit about this. He responded, "Yea, because I'm tied down so much. And you can see it out there, I haven't even had it out this year yet." The "it " he was referring to was the large new looking motor-home I had seen parked beside their garage in their backyard. It was so big you couldn't miss it. I asked whether this was usually when they would start camping to which he responded, "Oh by this time of year we'd have been camping three or four times… Oh yea, oh yea, when she (Mrs. Camper) was feeling better." He said that they would drive out to the Kananaskis as, "that's all she (nodding to his wife) can handle… So, as I say, I haven't even had it out this year yet, you know." His voice carried the sound of his frustration that I had come to know quickly. I wondered if her increasing disability was starting to cause some resentment in their relationship. I could see the longing in Mr. Camper's face as he stared out at the unused motor home. I wondered how he was coping with giving up his regular activities to be the caregiver.

I wondered if they were planning to go camping with the motor home this year. I asked if they thought they would get out, to which the response was that they would probably try while their son was home. Mrs. Camper spoke up saying that they wouldn't be camping until after Stampede was over. Stampede week in the city has been a long-standing tradition in many Calgary families, which consists of ten days of rodeo events, agricultural exhibitions and carnival activities. She said her husband hadn't missed a

Stampede in his lifetime. Mr. Camper agreed, and reminisced that they attended every year since 1958 when they had moved into the city from Banff. Mrs. Camper reminded him that even when they lived in Banff they had still come in for parade day.

Mr. Camper looked back with fondness to the year he and his daughter had spent the whole day down at the grounds together. "It was fantastic just the two of us. Just L and I, our youngest daughter and we were there for, we must have been there about eight hours. We left here in the morning and we never come home till…" Mr. Campers story was interrupted by his wife who asked where their son was that day. Ben jumped in teasing, "It doesn't matter, I mean Dad always liked L best anyway." Mr. Camper continues saying that their son must have been busy with something like baseball otherwise he would have been there too. Mr. Camper finished the story saying, "But that was when D (his wife) was good eh? and we didn't have to worry, you know? But now it's a little different. We don't know" I assumed he wondered if this year they could go down to the Stampede grounds. Would his wife go or stay home unsupervised, or would a family member stay with her? Mrs. Camper, understanding the unspoken question remarked, "Well there's nothing stopping you from going. I stay put. I know my limits. I've learned from this last fall." I asked whether Mrs. Camper thought she might go down to the Stampede grounds, picturing her in a wheelchair pushed by her family. She replied that she didn't think so. She described that she wouldn't be able to see anything and other people did not watch out for those in wheelchairs and she found them to be "quite rude" "Going down in a wheelchair all you get is elbows and ankles." I wondered if this was the real reason, or if she felt like she would just be a burden to them.

I asked what other things Mr. Camper felt he'd had to put on the "back burner" since his wife began falling. The answer I received was worse than I had anticipated: "Pretty near everything really. I've got to do the shopping when she needs stuff like this and that's one thing, I just love going grocery shopping. I just jump for joy, do cartwheels and I just spin around all the way to the store." I had to laugh at the sarcasm. I could tell he didn't like that particular chore but he had still kept his sense of humor about it. Mrs. Camper interjected talking about their recent shopping excursion:

> Well yesterday we went shopping and Dad (her husband) just about had a coronary didn't he? He was pushing the cart and B (their son) was pushing me and L (youngest daughter) was picking up stuff and every time L put something in the cart he's thinking Holy, when is she going to stop. But I only do this once maybe every five or six weeks, eh? That's what we did this morning. We just re-wrapped all the meat. You get it in the big packages and then you put it into smaller ones. I stood and held the bags open while he dropped everything in. I try, eh Dad?

It occurred to me then that both spouses had given up a lot. I said out loud that Mrs. Camper had given up a lot as well, to which she lamented on the activities they were no longer able to do:

> I mean I can't sew anymore. We used to go bowling. I don't bowl anymore. We used to go dancing, I can't dance anymore. We used to go walking through the campground; I can't do that anymore. The only thing I haven't given up is my jigsaw puzzles-two fingers.

I wondered what supports this family received. How much did the younger daughter give of her time, where was the older daughter? Did they receive home care assistance as well? I asked how much their younger daughter did for them, from their earlier comments, I was beginning to think she did a lot. I soon found out how correct I was. Mrs. Camper was quick to answer my question saying, " I don't know what I would do without L because she does the banking and she comes in at night and helps make supper and cleans up and…" I interrupted to ask if this occurred every night. "Monday to Friday and she comes on Sunday. Saturday, we usually go out for lunch." Was the answer I received. I wondered if she was married or had children to work around. I found out that she was single and one of the dogs I had met previously was hers. Mrs. Camper explained that the other dog belonged to their other daughter.

I inquired if their other daughter was as helpful as the one they'd been extolling me about. Mrs. Camper lamented:

> Not like she used to be. She used to do a lot for me but since she's been living with this guy, she doesn't do too much I sometimes think she could do more for me but I won't ask her anymore. I figure if she doesn't want to do it willingly, I mean, I never have to ask L to do anything for me, she just knows what needs to be done and she does it. That's like B. He came home just to give everybody a rest and he's been here for almost a month.

I was happy they received so much freely given family support. I was intrigued to know what sorts of tasks Ben had taken over for his Dad and sister while he was here. When I asked him what sorts of things they'd asked him to do he replied, "Everything." I asked if "everything" included shopping to which he replied, "I don't like doing it either but…." Remembering his father's earlier comments about turning cartwheels I asked him if he felt likewise, My flippant question brought his somber reply, "Well I don't think I can do cartwheels but you know, it has to be done so we'll do it. Family is pretty important." Ben also stated that while he was here he had been helping his dad and his sister with their regular chores such as the laundry, watering the plants, vacuuming and dusting and other cleaning.

We talked about outside assistance that the family received. Mrs. Camper explained that they have someone from home care come in for three hours a week to help with chores such as dusting, vacuuming, washing and ironing. Mrs. Camper voiced her displeasure at the lack of quality in the work that they performed. She said she has had several different workers in and all of them did not clean, as she would have liked them to. She went on to explain:

> I don't think I have had one girl that does anything right. I was just telling B last week, she left and I went into the den to sit on my chair with my feet up and I looked down and saw this dead fly on the table sitting there by the lamp. I thought, she just left the house, she just finished dusting. So I didn't move it. I thought, I'm going to leave that there and see what happens when she came yesterday. The fly is still there so I guess L will have to dust. So, she never dusted the den at all. And she didn't dust in the dining room and I don't know whether she dusted in the living room because I can't follow her around… I don't know where they get these people from and I hate to keep complaining but I'm not happy. Because my house is not the way it should be…. I get really, really upset. There's no use laughing. I'm a fanatic, I know. I'm not as bad as I used to be.

They talked about wanting to hire a cleaning company to come in and give the house a thorough cleaning but were not sure if they could afford it. Mrs. Camper said it wasn't so bad when she had two hands and could do things like folding and hanging, but she has been particularly frustrated lately since her right arm has been put in a cast.

Mrs. Camper explained about other assistance she receives from home care. She said she had been receiving home help for the last ten years because of her severe arthritis. She also receives assistance for bathing and had bath bars and a lift installed to enable her to get in and out of the tub.

Mr. Camper spoke about the picture he had taken of his wife's wheelchair inside the van (not shown). I asked what the meaning of it held for him. He described it as follows:

> I had a beautiful car, an Oldsmobile, a fantastic car. And when my wife got arthritis, we had to have the wheelchair, then we had to put it in the trunk. When you put it in the trunk, there was no room for nothing else. If we went anywhere you know. So I had to buy the van in self-defense so we could put the wheelchair in the back and all the rest. Yea, that's what I say. There's a lot of things we've had to change really. I can see why people, when one of the spouses, man or woman, gets in that position, I can see why they walk out. I really can. They just say, to hell with it and they're gone.

Mr. Camper continued to voice his ongoing frustration that technology hasn't been able to help his wife. I had heard in his voice that sometimes he wanted to leave this situation he was living in. He felt trapped and tied down, unable to get things done, unable to travel freely. Even having breakfast with old friends or going to the Stampede for the afternoon and leaving his spouse alone was a concern to him and wasn't taken lightly. I heard many of the same words from him about wanting to escape as I had with another participant whose spouse too had fallen several times. Both experienced feelings of confinement and longing to have things the way they used to be, both wanting to get to the root of the falls and prevent any further injury.

Mr. Camper also verbalized his concerns about the possible drug interactions between the medications his wife was taking:

> I mean when I see her taking this stuff in the morning, she holds her hand out and you just pour them in there and one is just counteracting the other. It can't be doing you any good. And every one of the medications says it causes dizziness; well you multiply that by ten times, that's what's happening.

Mrs. Camper got out her dosette to show me the medication she currently takes. I recognized most of them, but she was able to tell me what they were: vitamins, stool softener, hormone pill, and Prednisone a steroid for her arthritis, one for her high blood pressure, aspirin, and one for her thyroid. Seven pills in all. Some she took more then once a day. She also needed a pill to help her stomach from all the other pills. She said she wasn't pleased with the care she had received from her current family doctor and was looking for a new one. She wanted to try and reduce her pills if possible and wanted her new physician to help her do this. Ben assured us that before he left to return home after the summer he would help her find a new doctor. Ben remarked, "Yea, there's a few things around here I've got to get straightened out before I go back." It sounded as though there were several other issues that Ben felt he needed to resolve prior to his return from his holiday. I wondered what else he was going to try and help with.

Our conversation was interrupted by the dogs that started playing at our feet and lightened the serious mood pervasive in the room. After some discussion of how entertaining they were, I made arrangements with Mr. Camper for our next visit. As I was leaving he told me how much he had enjoyed our talk. I felt glad, as I had too. I thought that even though I wouldn't be able to help his wife, perhaps talking about his experience might help him reduce his stress by having someone to vent to.

Visit Three

As I came around to the side gate, I met Mr. Camper for our third visit. He was coming in from outside, looking like he had spent the day gardening. I asked him if he was managing to catch up on all his outdoor work now that it had stopped raining for the minute. He replied that he didn't think he would ever catch up. Shaking his head he exclaimed over the amount of work he had left to do. We decided to take advantage of the beautiful day and sat outside on their cedar deck. Pointing to the thick crop of raspberry bushes, Mr. Camper used them as an example of his predicament:

> Well, as you can see eh, all of this you know and it all takes... like those raspberry bushes, I didn't get at them in time and there's lots of dead stuff in there that should have come out.... It's just unreal. Then I didn't get the peonies tied up in time and as you can see they're just about lost now.

I asked Mrs. Camper if she had been able to help with any of the planting or sprinkling of the seeds. I thought perhaps she might be able to help in this small way, and in doing so, feel better about herself. She replied, "No, I haven't done nothing. I haven't done anything since the beginning of April." I knew she was referring to contributing to the running of her household. I imagined that she was perhaps feeling useless and was frustrated at not be able to help. Mr. Camper responded to this stating, "Well if they could ever find something for that arthritis and the dizzy spells, you'd be 100% I guess." I knew he desperately wanted a cure for his wife's ailment. He wanted nothing more then to resume their life that had seemingly ended a few months ago.

I was not optimistic that help would be found for his wife's arthritis, although new medications are invented daily. I knew from our previous visit that she had seen a physician specializing in arthritis and that she had tried "everything" available for arthritis at the time but nothing had really made a difference, or had found that the side effects were worse then the benefits. I hoped the dizziness was caused by something that could be diagnosed and treated. I knew she was seeking a new physician so I encouraged Mrs. Camper to be honest with all of her problems. I knew that sometimes seniors minimized their complaints and the seriousness of them and I did not want her to do that. I also encouraged her to write things out a head of time and to bring her list of what her concerns were, medications she is taking including vitamins and over the counter medications, as well as questions she wanted to ask. Once people get into see their doctor they often feel rushed or intimidated or stressed enough that they forget what they want to say or ask.

I asked Mr. Camper if he wanted to talk about the photographs he had taken. The first one showed the motor home and the truck used to tow it. We had talked about the possibility of them going camping during our last visit. Mr. Camper commented that the picture showed something he dearly loved to do and hoped to continue doing soon.

He said that while his son is here visiting they were going to try and get out to a nearby campsite they had frequented in the past. We talked about the logistics of his wife getting around. The ground would be too uneven for her to ambulate safely, even with her walker. They would have to bring her wheelchair. I knew it would be awkward in spots and I was glad their son would be there to help. They said they would take the walker, "We take it because I use it inside the trailer especially at night if I have to get up and I need something to hang on to." I told them that it sounded like a very brave adventure and that I admired their courage. I knew that although the trip wouldn't be easy, their beautiful trailer would make the usual hardships of camping less acute. Mrs. Camper said that they were willing to try it once, but a lot depended on her visit to the doctor tomorrow when her cast would be assessed.

I chuckled when I saw the next picture showing the plentiful garden we were just talking about. Mr. Camper emphasized the amount of work involved in caring for the rose bushes and flowers when he spoke about the picture and the work he could never seem to finish:

> And you see (pointing to the photo and then the garden); all this stuff has got to be trimmed back too eh. And that's what I say, I've still got all that to do and it's all got to be cut down and shaped and everything else and I haven't had a chance to get at that.

I knew things were made worse for him by the amount of rain we had experienced recently. I realized his opportunities to get outside to work when it was dry were few. He said that since his wife's worsening mobility he was required to do things indoors that he wasn't use to. He was grateful to his daughter for all of her assistance and credited her for helping to keep things going. I thought that perhaps he felt ill equipped to handle things in the areas of his wife's usual domain. I wished I had asked him if he had any previous experience perhaps growing up, with domestic chores. I found myself wondering again as I had with previous participants, if they could manage without the assistance their family provided. I also wondered if Mrs. Campers' physical health worsened how much was her husband willing to take on and for how long? If she was no longer able to live at home would they both move? What had they thought about this or their future? If they were unable to live in their house, what did he think was the next best alternative? I wish I had asked these questions. Perhaps I would get my answers later.

During our previous visit, Mr. Camper had talked about a new hearing aide he'd recently purchased. It was in a different ear than his last one and, as a result, he was having problems getting used to it. He told me that they had assessed his hearing and found his other ear to be less impaired so they recommended that the aide go in it. Mr. Camper thought that was strange he wondered why because he could already hear fairly well in that ear and shouldn't the aide go in the one that needed the most help. I told Mr. Camper I thought he had good rationale. Mrs. Camper said that he probably could use them in both ears. Later her comment made me wonder where his old hearing aide had gone. Do they get traded in? I thought that he would probably find it useful now.

I asked him if he was used to his new hearing aid yet. He replied, "Not really, I haven't got it in. I never wear it until I.... I don't like to put it in when I'm in the yard and stuff like that because if you're bent down and you catch it..." I understood what he was saying. I knew hearing aides were very expensive and few seniors could afford to replace them once lost. I remarked that it would be too expensive to lose in the lawn. I was quickly informed that Mr. Camper's new aid had cost $1,100.00. I was taken aback by this realizing how much money that was to someone living on a fixed income. I encouraged him to return to where he had bought it and get something that he would wear regularly. He said he had planned to but something always came up to disrupt his plans.

Mr. Camper turned to the next photograph he had taken of the deck we were currently relaxing on.

I had admired the cedar deck that ran the full length of the house, on my previous visits. It was attached off of the kitchen and could be viewed from where we usually sat inside. Mr. Camper said that he had built it prior to when his wife began falling, when he had the time and energy to do things like that. He commented that there were still things he wanted to add to the deck to enclose parts of it, but he wasn't sure when he would get the time or money to do what he envisioned. He also pointed out the bush at the end of the deck in the photo. He said that it was one more thing that needed his attention that he hadn't yet gotten to. Looking at a large patch of rhubarb in the photograph I thoughtlessly remarked that with all of their rhubarb and raspberries I knew what kind of pies they would be baking. Mrs. Camper responded that she was unable to make pastry anymore. "Well L helps. She did that at Christmas. She did all of the baking at Christmas because my hands weren't good enough." I wondered if she felt as though her life was on hold, particularly since she had lost the use of her dominant arm. It didn't surprise me that her daughter had once again stepped in to lend her much needed and appreciated assistance.

Continuing on with our discussion of assistance, I asked if they knew their neighbors. I knew many seniors who relied on their neighbors for social and sometimes physical assistance. I found out that the Campers had lived in their home for forty years as had most of their neighbors. Mrs. Camper remarked that several of their neighbors were the original owners of their homes. I found out that the "newcomer" to the neighborhood had lived there "twenty years at least." Mr. Camper laughingly reminisced about helping this neighbor in the past to park his motor home, after he had attempted once and taken off the corner of the Campers' garage. Mr. Camper said that his skills did improve eventually and Mr. Camper was no longer required to park it for him.

Both Campers remarked on how fantastic their neighbors had been to them over the years. It sounded like a very close knit community that surrounded them. Mr. Camper said that knowing Mrs. Camper had been unwell recently, several had sent over pies and other food. Mrs. Camper remarked, "I know if we needed help, they'd be there to help us." Mrs. Camper related the details of a traumatic time when the neighbors were there to offer assistance:

> I think if we ever needed any assistance… Like that last time that you took me to the hospital. The ambulance came up and it was about 11:00 at night. And these to young fellows here, they were out like a shot when they saw the ambulance. They came to find our if they could help. Then when I came home from the hospital the other neighbor here got me into the house. He came into the house and pushed the table out of the way and he almost carried me up the steps.

I admired the way that the neighborhood had banded together to help each other out. I thought how fortunate it was that they had, as their help was certainly welcomed now. Envisioning the neighbor helping Mrs. Camper up the stairs after coming home from the hospital reminded me of the front of the Campers house. I had to ask them who looked after their front lawn as it looked like a back breaking task.

I asked Mr. Camper how he managed it. He replied that he still looked after it saying, "It's a little bit of a chore. I don't know how much longer I'm going to be able to do it though, I don't know. You know, maybe a couple more years if I'm spared." I knew he was thinking he could manage it unless he became sick or disabled himself. He said they could not afford to pay for someone to cut the grass for them. Even the neighbor boy was charging $25.00 a week. Mr. Camper continued, "Oh yea. There's a lot of work to do around here. A lot of work to do."

I remarked that his work was not just outside but inside the house as well. He nodded hi head and shrugged his shoulders as if to say, "what other choice do I have?" Once again their daughter Lilly was commended by both Mr. and Mrs. Camper for her regular assistance. Mr. Camper described their usual routine. "Before L comes home, we'd start supper and then L would finish it. Well a lot of times, like I say, I lose a lot of time in the morning too waiting for D (his wife)." I remembered from our previous visit that Mr. Camper doesn't like to go outside to work until his wife is up and settled somewhere.

Last time when we discussed his waiting for her to get up, Mrs. Camper had stayed quiet. This time she spoke up saying, "I don't know why you wait for me. When I get up I can always holler at you." Mr. Camper replied, "Yea well sure if I'm around the front or something and then you can't open the door." Mrs. Camper continued, "I'd just sit and wait for you." Ben their son, who had been observing us quietly while he cleaned up the kitchen and started supper, interjected into his parents conversation saying, "That's why you've got to get a pager." He sounded exasperated as if he had had this discussion with them before. Mr. Camper wanted to install an intercom system. Mrs. Camper wanted to get a baby monitor. I thought they were all excellent ideas but thought that the baby monitor was the most practical and least costly suggestion. I wondered if they were aware of the lifeline service Calgary offers or perhaps a cell phone might be the answer they were looking for. I offered up these alternatives to them as well.

Although he worried about not being able to hear her if she fell or needed help, Mr. Camper described one fall that he had no trouble hearing. He said he was able to hear her fall as he was downstairs and heard the crash above him. He likened her landing on the floor as sounding like "a ton of bricks". He said he was worried it might come right through the ceiling "I came running upstairs and there she was laying between the bathroom and the wall. I didn't want to move her so I called 911 and they were here within a couple of minutes." Mrs. Camper continued:

> Five minutes and they were here. They were really fast... It was 11:00 at night; the other one was 11:00 in the morning... They had a hard time getting me out because I was jammed between the doors but I knew I had hurt something in my bottom half because my leg was all twisted and I said, 'Just pull my leg straight.' So he managed to get my leg straight out but I couldn't move and they had to put me on a backboard...That's twice we've had the ambulance.

I could understand why Mr. Camper felt uncomfortable leaving his wife to go outside. Mrs. Campers' fall history sounded traumatic for them both. I asked Mr. Camper if he thought getting a baby monitor would allow him more freedom. His wife answered, starting a verbal tussle that again made me wonder if the strain of her falls was causing some resentment in their marriage. Mrs. Camper said:

> Well especially when he is downstairs because I can just stand here and holler and holler and holler. Just like this morning, I must have called you five times. I was in the bathroom and you didn't hear me so I finally got up and went into the bedroom and you were sound asleep, sawing logs.

Mr. Camper remarked that he had been outside working until very late last night because it had finally stopped raining. He said that he was probably so tired he slept through her calls. Mrs. Camper said that she told him to quit when he came in for supper:

> You never listen. The trouble with B (Mr. Camper Sr.) is that he never knows when to stop. I tell him, 'It'll keep if it doesn't get done.' Look how many things I have to leave undone. I have sewing projects that I never got finished and I don't think I'll ever get them finished, like blouses for L. I've got three blouses cut for L and....

Mrs. Campers' eyes filled up with tears. Seeing this, Mr. Camper softly tried to reassure her and offer her encouragement, "You never know, you never know. Once you get used to your hands again. Just take your time. I know what you could do in half an hour, now takes you half a week." Regaining her composure Mrs. Camper replied:

"Right now both B (son) and L (daughter) have jeans that need to be shortened. But tonight they're going to learn how to shorten jeans because I'm going to sit here and direct traffic. L has never used a sewing machine and the worst thing to learn on is a pair of jeans because they're hard to sew."

From the banter back and forth between the spouses I could tell that each of them was feeling there was so much to do and so little time to get it done. Mrs. Camper talked about how her expectations had been adjusted since she was unable to participate in caring for their home. She remarked, "I never thought I'd see the day that I'd put a table cloth on the table that had never been ironed."

I wondered if Mrs. Camper was afraid to be alone. When I asked, she replied that she didn't mind being left alone. I asked Mr. Camper if he felt comfortable leaving her alone. He replied, "A lot of times, no because you never know. Mrs. Camper explained:

> I don't go too far. Like from the dining room I sit and do the jigsaw puzzles a lot. And then I have a television in the back room and I sit and watch TV. But no, since I broke my arm, I'm pretty cautious. I don't want another, although I had a near miss yesterday didn't we Ben?' I was at the eye specialist to get my eyes checked and we came out and I was holding onto the wheeler and I was pushing it towards the elevator and they had a carpet in front of it there and the wheels caught on the carpet. I haven't got much strength so it went that way and I went this way. B just caught me but my forehead hit, I think it was one of those ashtrays that sit out there. If B hadn't been there, I would have been flat on the floor. I would have had a nasty fall but B caught me before I fell. Thank God he was right beside me. If D (Mr. Camper) had been there I think I would have fallen because D's reflexes aren't as good as B's and I don't think he would have realized what was happening.

Ben commented that he would phone the manager of the building the next day to complain about the carpet there being a hazard. Mrs. Camper continued:

> It kind of jarred me, it shook me up. But as soon as that thing started to go I go, 'Oh God, I'm going to fall again.' I just hollered, 'Ben' and he had me before I could hit the floor. Because the wheeler just fell right over onto the ground because like I say, I don't hold onto it, it's just more or less to give me enough balance to keep me upright.

Mrs. Camper said she was planning to speak with her home care nurse who was coming tomorrow for her monthly check about a four wheeled walker with a bench, as she found her current one very awkward. I asked if the nurse helped her bathe to which she replied that another girl came in twice a week to help her bathe and to get in and out of the tub, but she didn't believe she was a registered nurse, she thought she was a nursing aide. I found myself wondering again, what would happen if her care needs increased. How did

Mr. Camper feel about providing his wife's personal care? In discussing her home help, Mrs. Camper was reminded of how disappointed she was in the quality of the homemakers they had in their home to help with the cleaning. Mrs. Camper said that even though she had lowered her standards they would never get that low. Mr. Camper commented with admiration in his voice that the generals' wife was the best cleaning person they ever had and that no one else could take her place. They missed her terribly since she moved on.

We ended our visit by recapping what we had talked about. I wished them good-luck with their camping adventure and their visit to the Stampede. I thought again how brave they were and crossed my fingers in hopes that it would all turn out well for them.

Wanting to find out how their activities went over the summer, I phoned Mr. Camper in early August for an update. A younger voice answered that I had not heard before. When I inquired to speak with Mr. Camper and explained who I was, she told me she was their daughter "Lilly" and that her Dad was up at the hospital visiting Mrs. Camper who had been admitted. Not wanting to disturb them I waited to call again until the end of September, the same lady answered telling me that her Mom had been admitted again to hospital and was to get out the next day. I sent my regards and best wishes with her to take to her parents.

Final Impressions

I called the Campers to follow-up with them for the final impressions section of this study. I was interested to learn how they had been since I last spoke with them. I knew Mrs. Camper had been hospitalized twice last summer. I hoped she was better and was curious to know if her hospitalizations had been caused by more falls. I phoned on July sixth, approximately a year after our last visit. The young voice answered again, I told her who I was and the nature of my call and asked to speak with Mr. Camper. She replied that her Mom had passed away last November and that she would let her Dad know of my call. I felt terrible to have been a reminder to her of her parents in healthier times. I asked her to please give her father my condolences. I wondered later if Mrs. Camper had made it to the Stampede or camping as she wanted. I thought of the family celebrating Ben's fiftieth birthday in a few days without her. I was saddened by their loss and for a future so different from the one anticipated.

CHAPTER FIVE: DISCUSSION OF THE NARRATIVE ACCOUNTS

Introduction

Presented here is a discussion of the narrative accounts drawn from the previous chapter in the context of other research done in this field. Ordinarily this section is reserved for the explanation of previously determined themes or categories but because the method of "Visit" encourages that the co-created stories be left intact, theming was not part of the analysis. Instead, analysis with this method begins at the first visit where the researcher and co-participant decide what will be included in the story. The developer of this inter-relational method believes that nursing should hear the individuals story in its uniqueness and avoid preconceptions of possible commonalities within the experience. This researcher believes that looking at these common concepts within the individuals experience can give nurses a baseline from which inquiry into a persons story can begin, and perhaps the nurse can in fact gain a better understanding of the individuals unique perspective. To enhance this understanding, a second method, interpretive photography was combined with the narrative approach.

Interpretive photography involved having the co-participants take photographs of what they felt helped define their experience of caring for a spouse at risk for falls. The photographs were then developed and returned to the co-participants at the following visit. During the visit the photos were discussed and the interpretation recorded as part of the narrative of the visit. For some, the pictures represented losses of things like previously enjoyed past-times as was found in Mr. Campers' narrative. For others, they represented gains, in terms of added equipment such as bathroom aides found in many of the photos as well as others showing walkers and canes. The photographs represent another layer of explanation of the experience, a medium for capturing experience in a visual way.

Chapter two highlighted a review of the literature focusing on caregiving and falls in the senior population. It was established that the majority of the research was quantitative in nature and did not explore the caregivers' experience of living with a spouse who is at risk for falls. In addition to the literature discussed in chapter two, literature is introduced in this chapter that further sheds light on this study.

Concepts common to the co-participants are identified and described as; the significance of falls to the caregivers, sacrifice of self; marital discord and supportive relationships. These concepts are explored in this chapter within the context from which they were generated, the participants unique and individual narratives and photographs.

Significance of Spouse' Falls to the Caregiver

Throughout our visits, many of the stories shared by the caregivers centered on the significance the fall event had in their lives. It held great meaning to all of them, but for different reasons. The significance of the experiences were as unique as the individuals themselves. The intention of this researcher was not to lose the individual voices but to show the experience of each and the significance their spouses fall event had in their lives. Although they all shared the experience of caring for a spouse who had fallen and is at risk for falls, from there the similarities end. Below is described the significance the falls had for each of the participants and the related literature supporting or differing from these findings.

The Ables

What I found most compelling about my visits with Mr. Ables was the way in which his wife's fall had affected, yet not affected, their lives. There was a definite tension I felt between Mr. Ables insistence that nothing had changed for them as a result of his wife's falls, yet several things he said had led me to think that the fall affected them in ways they had not yet perceived or acknowledged. For example, during our second visit Mr. Ables described the circumstances of his wife's fall, the tests done following, and the medication regime that was started and finished with, "That's about the story I guess." I then said that it didn't seem like her fall had slowed her down much to which he replied, " No, except that she doesn't go out unless..., well at this time of year it's not a problem." His statement led me to believe that at other times of the year, when conditions are dubious, it is a problem. So although he states that her fall hasn't affected them, in the winter it is a problem. This tension exists over several other statements he made as well.

Even though his wife's fall had been "minor" in that she sustained no real injuries and they felt that it hadn't really effected them, to an outside viewer such as myself her fall seemed to effect many facets of their lives. Was the fall so internalized they could no longer see where it had changed things for them? New aides were added to the bathroom, thought was given to removing scatter rugs and appliance cords. Mr. Able made the statement that he was glad that the stairs were carpeted as she spent time downstairs doing laundry and her various hobbies. Several times he mentioned how she takes the car even to go just three or four block, "many times she would like to walk but she takes the car... and that has probably robbed her of some of the exercise that she should be getting." This fear of falling is well described in the literature. Mrs. Ables was lucky, she had her young age on her side as well as no previous mobility problems, advanced age and mobility problems are factors identified in the literature as putting persons who fear falling at higher risk for falls (Vellas, Wayne, Romero, Baumgartner, & Garry, 1997; Tinetti, et al, 1994). All of these facets I saw as significant where I think he saw them as inconveniences, new hassles of daily life. As a researcher, her fall was a central concept around which I expected their lives to revolve. To him her fall was a warning to be cautious and not take risks. A warning of what could have been. Their lives did not continue to revolve around her fall or worry of future falls. Their independence was not compromised and they had subsumed her fall into a past event, and gone on with their lives. This finding is not addressed in the fall literature, which continues to be primarily focused on quantitative studies exploring measurement tools and interventions. I still wonder if I had visited them in the winter if the tone of the visits would have been different, perhaps more serious as the thoughts of falling would be closer to the forefront of their minds due to the slippery conditions.

The Teams

To the Teams, the significance of Mr. Teams' falls was very different from that of the Ables. This is probably due to both the seriousness of Mr. Teams' incidents, and the fragility under which they were maintaining their independence. Mrs. Team relied on her spouse to assist her in the day to day activities. She commented that after his fall, "I was a basket case because I depend on him to such an extent and he does take very good care of me." Due to her visual disability she had more at risk then Mr. Ables, who could carry on physically without his spouse more easily.

It would be very difficult for Mrs. Team to continue to live on her own if anything should happen to her spouse. Mrs. Team did state that she intended to live on her own, perhaps moving to a smaller place if something happened to Mr. Team. As well she commented that she occasionally reminds her spouse to make sure she has enough money to live comfortably somewhere should she end up on her own. "I don't want to live with my children and I don't want to have to live in a subsidized room someplace." Her spouses' falls served as reminders of the precariousness of their situation.

Because her spouses falls were more of a concern when he left their suite to return their shopping cart back to the basement after grocery shopping she said, "And I worried every time he went back." Her worst fears were confirmed when he fell right outside the door to their suite returning from delivering the cart downstairs. Mrs. Team was required to care for her husband after his last fall under enormously adverse conditions. "He wouldn't let me phone the doctor. He wouldn't let me phone the manager… He lay for three days on the bed." She described further, "I couldn't get his clothes off him… He said, "Don't phone anybody. Don't you tell anybody I had an accident." It was no wonder her concern for his safety was so great as she was the one who would be called into a very difficult service. I knew caregiving was difficult for sighted individuals let alone trying to manage with no vision at all. Heroically, she somehow managed to comply with her husbands wishes and provide him care. Not only did her husbands falls mean she would be the caregiver, it was also a concern to her as she might have relinquish her current level of independent living.

Although I am sure that the Teams were not alone in their precarious living arrangement, little research could be found discussing the tag-team style of caregiving the

Teams were involved in. Ethel Shanus (1979) in her seminal article on research findings on support systems, captured the relationship most accurately, saying, " The spouse usually becomes the one who provides care. In many couples, the amount and scope of the care are extraordinary." (p.45). In reflecting back on the couples in this study, extraordinary captures them nicely. Ducharme (1994), in her empirical research on elderly spouses recognized that senior spouses, "are involved in a mutual exchange of helping behaviors on a daily basis." (p.185). Supporting these findings, Ade-Ridder and Kaplan (1993) identified marital changes with advancing age brings increasing interdependence for the aging couple. This finding is of particular importance because although this interdependence is recognized in the literature, the degree or depth to which senior couples depend on each other is not clearly explicated. The quantitative studies do little to identify the extreme caregiving situations elderly couples can find themselves in. This qualitative approach allows the depth of the experience of caring for a spouse to be made visible. In this way the reader can better understand what "interdependence" can really mean to an aging couple.

The Readers

The significance of Mr. Readers' falls was different again from both the Ables and the Teams. Mrs. Reader was fully capable of caring for her self should anything happen to her spouse. She felt she wasn't reliant on him in any way, physically, emotionally, or financially, particularly more recently since she assumed the bookkeeping as well. No, the significance to Mrs. Reader of her spouses' falls, particularly his first fall, was a point in time she could recognize as being the start of his physical decline and increased need for assistance. In fact, Mrs. Reader said, "You know, his head knows what he wants to do but the message doesn't get there. Apparently that was the initial problem when this experience began seriously in 1995 or 1996." She had pinpointed his first fall as the time when things started to go downhill. As our visits progressed and our relationship strengthened she opened up further to me. She confided that nothing bothered her more since he started falling, than his bladder incontinence.

She had told me in our third visit that she was always a private person and was deeply embarrassed at the male bodily functions. She said she had booked an appointment for him to get some tests done by the urologist in case there was more to his incontinence than the water pill he took and the difficulty he had in getting to the bathroom due to his frail physical condition. He was at one time her lover, her friend, the father of her children, but their relationship had changed after his emotional breakdown, some forty years earlier. She was fearful of the day he would no longer be able to change his incontinent pads or wash himself.

She had referred to this in our second visit when we discussed the picture she had taken of her husbands bathroom remarking how it allows him to be independent, "Well yes, because of what use would I be. I mean sure, I can wash his back." I remembered how surprised I was at her comment because she just seemed so capable. I hadn't fully realized the degree to which her statement that she was a "very private person" extended. This is different from most of the caregiving literature that lump caregiving tasks together and assume that one task is the same as the next for female care providers, although the literature delineates the provision of personal hygiene as an area of discomfort for male caregivers (Gregory, Peters, & Cameron, 1990). Many researchers have identified caregiving as a natural extension of the female role in the marriage, an expectation (Seltzer & Li, 1996, Ade-Ridder & Kaplan, 1993), but as was found with Mrs. Readers' stories, this is an assumption that needs to be confirmed with caregiver.

Unlike formal caregivers' these informal spousal caregivers did not choose to become caregivers. Because of her proximity in living in the same house, and lack of physical disability severe enough to prohibit caring for her spouse, she was naturally nominated as caregiver. This type of caregiver selection is well supported in the literature (Fengler & Goodrich, 1979; Allen, Goldscheider, & Ciambrone, 1999) The significance of Mr. Readers' falls was that now Mrs. Reader was forced into caregiving for a man she wasn't sure she even liked. She struggled with the confusing emotions.

Mr. Readers' falls were also significant for her in that it added new worries. In our visits she had described him as being a, "twenty four hour concern" to her Although she said that she didn't worry about him when she left the house, the preparation she described for her to leave him comfortably, for them both, was immense. His falls had added these additional stresses to an already stressed marriage. The Campers were enduring similar circumstances.

The Campers

Mr. Camper had placed an entirely different meaning on his wife's falls. The significance of them to him was twofold. Firstly, he was "tied down" he felt he couldn't leave his wife alone. When he did leave her for his Thursday morning coffee meetings with old work buddies, he worried about her. He delayed going outside in the morning to do yard work until his wife awoke, usually two hours after him. Concern over her falling had disrupted their lives to such a degree the frustration was palpable. Mr. Camper lamented several times about the yard work he could never quite catch up on. From his extensive terraced lawn to his runaway peonies and delphiniums, he was never able to stay on top of the care his house and yard required.

The second meaning his wife's falls had to him was similar to that of Mrs. Reader, his unasked for and unprepared for, call into caregiving. Interestingly though, the two experiences with this calling were very different. Mrs. Reader was expected (she felt) to provide a certain amount of care for her spouse. "Which is alright", she said, "I expect to do them." (Referring to expectations her husband has of her). It wasn't until very recently that she began to receive outside assistance when he required help with his personal hygiene.

Mrs. Camper, on the other hand, had been receiving help long before she started falling, due to her severe arthritis. At no time was it an expectation that Mr. Camper provide her personal hygiene. This gender support difference will be discussed in more depth in the "supports" section. Mrs. Camper had a bath lift installed and home care assistance once a week for bathing for the last ten years.

Despite his not having to provide personal care to his wife, there were other expectations he did have to look after that were new and caused him great displeasure. One these, he mentioned was the grocery shopping. " I just love going grocery shopping. I just jump for joy, do cartwheels and I just spin around all the way to the store." Looking after the houseplants, the laundry, the ironing, the bed changing were other areas he never had to worry about before his wife became so disabled. He'd had to take over even more since she had fallen and broken her wrist on her dominant hand and was unable to assist with anything.

His frustration with being “tied down” had helped him to understand why some spouses leave when they can no longer cope. He told me, “I can see why people, when one of the spouses, man or woman, gets in that position, I can see why they walk out. I really can. They just say, to hell with it and they’re gone.” This was how significant his wife’s falls were to him. I know these same thoughts had crossed both Mr. Campers’ mind and Mrs. Readers as well. The phenomena of this resentment for feeling tied down has been identified by Ade-Ridder and Kaplan (1993) in their work on spousal caregiving. This strain can affect their relationship although the literature is less clear on this aspect.

Summary

Unlike professional caregivers who might see the spouses fall event themselves as of primary importance, the spouses saw the fall events in a variety of ways. For the Ables it was a warning, an event that occurred where the outcome could have been much more serious. For Mrs. Team it was a time when the roles were reversed. When her usually caregiving husband now required her care following two serious falls. For Mrs. Reader and Mr. Camper the falls were points in time, signaling the beginning of a time of caregiving (Ade-Ridder & Kaplan, 1993; Brubaker, 1985; Fengler & Goodrich, 1979). This has also been described by some literature as the transition into the caregiving role (Kramer & Lambert, 1999, Seltzer & Li, 1996). All of the co-participants, except for the Ables, saw the events as not the fall itself that was meaningful but what it now meant, the situation the falls had contributed to in which they now found themselves living was the actual significance of the falls. Although the falls may have been "a warning" for Mr. and Mrs. Ables, for the others it was something entirely different. For Mrs. Team it was being a blind caregiver all alone prevented from asking for help. Her husband's falls too served to remind her that one day she might be on her own and had helped her prepare for that in the future. For Mrs. Reader it was a beginning of a time she felt poorly prepared to deal with, physically or emotionally. For Mr. Camper it was a time of feeling "tied down", a time when he was not able to feel the satisfaction that comes with a job that's completed. He struggled daily with caring for his home and wife, a territory that was vastly unfamiliar to him. This caring was confounded by the unending worry about his wife's risk for falls, causing him to change his usual routines and inhibit his out-door activities. The falls do not seem as important as themselves but more as a symbol of their spouses declining health and physical ability. They seemed to be something the caregivers could point to saying this is where things started to get worse or this is where everything started to go downhill. This was certainly true for both the Readers and the Campers.

Sacrifice of self

I have called this section 'sacrifice of self' because of the heroic stories I heard from the co-participants about their experience of caregiving to their spouses. All, except the Ables, had poignant descriptions of the sacrifices they have made. Each caregiver desired to provide their spouse with the best care they could, no matter the state of their relationship with their spouse. The caregivers have shared their most honest and intimate accounts of the ordeals they have suffered, for some because of a commitment to their long-term marriage, for others, out of a sense of duty or obligation.

The Ables

Although Mr. and Mrs. Ables had been married for almost fifty years, their caregiving stints for each other over minor illnesses and surgeries had been short and non-critical. Mr. Able recognized that there would likely come a time when either he or his wife would be called into caring for the other. He felt that:

> As long as neither of them is a real invalid and one of them is in fairly robust health, I think you can always make out in your own home. Because you can always look after your spouse to an extent… We've always looked after each other and I would imagine we could manage that up to a point anyway, if one of us took a bit of a turn.

Mr. Ables perspective was fairly accurate with his identification of two significant characteristics other researchers have similarly found for keeping a spouse at home (Braithwaite, 1996). It was found if the care receiving spouse is not an invalid, and if the caregiving spouse is in fairly robust health, the caregiver has a better chance of helping their loved one remain at home for as long as they are able to assist them. But, if either spouse is more frail, particularly the caregiver, or if the care receiving spouse requires extensive care, then self sacrifice on the part of the caregiver occurs prior to death or assisted living facilities, including nursing homes. The other co-participants shared their experiences of caregiving and the selfless act of caring for their spouse under very complex and adverse conditions.

The Teams

Mrs. Team described two incidences of great self sacrifice when she provided care to her spouse following his first fall which had resulted in a fractured pelvis, and following his last fall exactly a year later, outside the door to their suite. It was this latter fall where her self-sacrifice was most evident as he forbade her from calling anyone for assistance. Desperate to keep the fall a secret, Mr. Team did not even tell his wife at first. Mrs. Team described, "He was going to have lunch and then he said, 'No I'm not.' And finally he said, 'You know, I fell.'

He required her to provide him care for three days while he lay on their bed recovering from what she guessed to be a re-injury of his fracture. I knew that it was entirely possible for him to have re-fractured his pelvis as it takes several month for such an injury to heal and, due to a variety of reasons, the healing time is increased as we age.

It was likely that he was not yet fully recovered from his injury when his second fall occurred. She told me about her struggle:

> He could swing his legs and sit on the side of the bed… after about three days, but then he couldn't get turned around to get back… So, I'd lift his legs and shift him around and had to pull all of the bedding off the bed and then put it back on the bed when he got in… You know, everybody said, 'why don't you ask for help?' but he wouldn't face that.

She sacrificed her self to care for the man who usually cared for her. She did it alone to help him save face; her commitment to him was so great. I had difficulty understanding this intense offering of devotion to a man she had painted as very controlling. Was there other motivating factors I was not aware of? Could she have been worried about future repercussions from him if she did not abide by his wishes? It only crossed my mind as one possibility only because of the high incidence of abuse in the senior population.

"Many seniors are reluctant to report a fall as they fear a loss of independence, changed perspective by their families, and institutionalization."(Jewell, 1997, p.8). This was certainly the case for Mr. Team who was adamant that his wife not tell anyone about his last fall. He was so firm about this wish that his wife struggled for several days to care for him all by herself, inventing toileting and repositioning techniques as she went. This clashed with what she really wanted to do, causing her quite a dilemma, but as often is the case with caregivers she honored his "poor" decision (Rutman, 1996) She perceived that she had little choice in the matter, as is often the case (Farran & Keane-Hagerty, 1991). After all she would have to live with him if he went to the hospital and then came home to likely resume his caregiving role. Often the caregiver is thrust into the role with out realizing until it is well underway, after the initial crisis has settled down.

The Readers

One truly heroic example of self sacrifice was noted in the stories Mrs. Reader shared. Once married to a man she loved she stayed married to him when he changed after his emotional breakdown. She now questions why she is caring for a man she isn't even sure if she likes anymore. There were many examples she gave, throughout her narratives, of staying and looking after her spouse out of a sense of duty and obligation. During our final visit she opened up and bared her soul. I don't believe she would have shared her emotions so freely during our third visit had we not met for the previous visits. Although she had shared openly in our first two visits, it was certainly not the same as the fresh raw emotion I witnessed in visit three. I felt privileged by the depth of her trust. This illustrated to me the value of a relationship built over time.

Describing the reason for her distress on our third visit, she told me that she was not able to bring herself to caregive to her husband any longer. She was emotionally and physically exhausted. Yet, when her spouse went AMA from the rehabilitation program, and showed up at home escorted by her son, she did not have any choice. The worst part of his arrival home, she told me, wasn't that she would have to resume her caregiving duties, but that he had peed on the lawn in front of the neighbors. She told me it was something she would never get over. "I despise him for doing that to me", she said. She had directly related his public incontinence as a personal affront. Mrs. Team was exhausted with caregiving; this is referred to as burnout, or role strain, by researchers. I was sure the Mr. Reader had not intentionally urinated to upset her, likely he had some urgency and could not wait for more private and acceptable quarters. He probably had no inkling how severely his actions had affected her. Not anticipating him home quite so soon and so debilitated, she was perhaps reacting out of fear and anxiety, feeling unprepared for what she must immediately face.

She had told me that caring for him was even more difficult as he had actively avoided helping her when she was ill and needed assistance in the past. This past inaction made thoughts of reciprocity a questionable issue. Further meanings of reciprocity shared by the co-participants will be discussed in the section entitled "marital discord". Mrs. Reader had given up her friends and family while he was acutely ill and in the hospital and had stopped seeing friends prior to that. Her close family ties mitigated her sacrifice of her social supports when she needed them most. I knew the life she was living currently was far from what she had anticipated but probably in part due to traditional gender roles (Palo-Stoller & Cutler, 1992) she expected to stay and help her spouse until she could no longer physically manage. She didn't realize that her mental health was equally important.

The Campers

Mr. Campers' stories of self- sacrifice relate to his devotion to his wife and his desperation to get at the root of her dizzy spells, which were causing her falls. Stricken with rheumatoid arthritis, her bones were made weaker by the steroids she had to take. During my visits with her spouse her dominant arm remained in a cast. I later discovered she had a fractured wrist, the result of another fall. Her fracture, combined with her arthritis now inhibited her from her usual tasks. Mr. Camper took on additional household duties of which he had limited practice. Meal preparation, dishes and laundry were areas he was quickly trying to master as a caregiver, sacrificing beloved activities in the process.

> I got so much work out there I don't even know where to start. And, as I say, I get up every morning at 7:30 and I have my breakfast and I'm all finished by 8:00, you know. Then I gotta wait until D (his wife) gets up and she doesn't get up sometimes until 9:00 or 9:30, sometimes 10:00. Well I could be doing a lot of things but two hours is gone right there, eh?

A naturally early riser, Mr. Camper would wait until his wife awoke, usually two hours later, to assist her with her morning care and breakfast. Once safely settled, Mr. Camper could then go outside to attend the multiple demands his large yard commanded.

Sacrificing projects he had started in order to become a caregiver, a role he had minimal preparation for, Mr. Camper took on unfamiliar and unwanted tasks.

When I questioned him about what else he had sacrificed for the time being he replied: "Pretty near everything really. I've got to do the shopping when she needs stuff like this and that's one thing, I just love going grocery shopping. I just jump for joy, do cartwheels and I just spin around all the way to the store." Although he meant his words to sound light hearted, I heard the undercurrent of frustration at the thought of this task.

Another sacrifice Mr. Camper lamented about was giving up his favorite car when his wife's disability worsened to the degree that she needed to use a wheelchair when she went outside of the house. He told me:

> I had a beautiful car, an Oldsmobile, a fantastic car. And when my wife got arthritis, we had to have the wheelchair, then we had to put it in the trunk. When you put it in the trunk, there was no room for nothing else. If we went anywhere you know. So I had to buy the van in self-defense.

This sacrifice was so important to Mr. Camper that he took a picture of the van that had replaced his car to describe what his experience was like caring for a spouse at risk for falls. Unfortunately as the photo had been taken against the sun, it did not turn out well enough to be reproducible here. I couldn't think of a more honest representation of his sacrifices. He couldn't even begin do describe all of the changes they had been through, not only since his spouse began falling, but prior to that with her worsening arthritis.

I was concerned for Mr. Camper as he was showing characteristics of someone who is becoming burdened. Worry, loss of sleep, lack of time for social and recreational events contribute to the development of caregiver burden (Chenier, 1997). He was displaying all of these. I knew he was under terrible strain and I was glad his son had come to help him for the summer.

Marital Discord

Although the caregivers were working hard to keep their spouse at home, As in most marriages, both parties contributed to times of marital discord. All of these couples were in long term marriages, successfully weathering past turmoil. I felt awkward and confused by some of the comments the caregivers made in front of their spouses. I wasn't sure if they were meant to be as hurtful as they sounded on the surface, to an outsider. I tried to judge whether the words had the same affect on the care receivers as they did on me, by watching for their reaction to the words, both verbal and non-verbal. An example of this is the tension I felt when Mr. Camper complained about his wife sleeping two hours past him and how it delays him getting things done. The first time Mr. Camper discussed this, Mrs. Camper stayed quiet. A couple of visits later when he revisited these comments she reacted back, telling him that he doesn't need to be waiting for her. I wondered if it was perhaps in part, a generational issue that I was experiencing. I was used to spousal equality and the sharing of all tasks and chores. For the co-participants, the traditions they were raised with were quite different. Both Mrs. Reader and Mrs. Team made comments on the generational differences of the men of their day and men now.

A positive marital history has been noted by researchers in many fields as being pivotal to the success of the caregiving situation, in particular, for the caregiver. This has been well identified in the dementia literature particularly research on Alzheimer's disease and its' sequelae (Knop, Bergman-Evans & McCabe, 1998). However dementia is an insidious disease and caregiving would be initiated gradually. Falls, on the other hand, are an acute event, a crisis situation not only for the person who has fallen, but, as this study has shown, for the caregiver also. Care initiation was sudden for Mrs. Team and Mrs. Reader, coming in the midst of otherwise normal lives leaving them no time to question their nomination, as these spouses have discovered, this is similar to Strawbridge, Wallhagen, Shema, and Kaplans' (1997) finding in their study on senior caregivers. Because of their proximity, spouses are the natural choice for primary caregivers of disabled spouses (Stoller & Cutler, 1992). Caregiving does not always equate with untroubled marriages though. In fact, quite the opposite might be true. Caregiving can worsen already fragile ties.

Closely tied in with marital discord was caregiver burden or strain. The two intertwined one feeding into the other around in a cycle of strain and frustration. Because these two concepts were so enmeshed within the caregivers' narratives, caregiver burden will be discussed as it influenced the marital relationships for the spouses in this study as a subsection under each co-participant.

The Ables

The Ables had been married since 1953 and could well be considered as a "long-term marriage. Their relationship seemed to fit with what Goodman (1999) discovered in her study. Goodman found that long-term married couples were the happiest when each spouse gave equally to the relationship. The Ables did not express any concerns or issues regarding their marriage therefore I can only assume that there were none, or none they felt applied to sharing their experience. Perhaps related to the lack of marital discord was the lack of needing to give care and therefore no imposed burden or role strain to cause marital friction.

The Teams

The overwhelming relationship issue I identified following my visits with Mrs. Team, was her spouses' intense need for control over their lives. As she told her stories I wondered if her husband might even be satisfied in some way that she was now completely blind, leaving her entirely reliant on him, giving him the ultimate sense of power and control. Fortunately, Mrs. Team is a strong women who has demonstrated she is not afraid to assert herself when she is fighting for something she believes in, her independence for instance. She gave several examples of times she had stood up to her spouse to retain the few skills she still feels comfortable performing: "I've made muffins. I had the recipe in my head. And I can make baking powder biscuits, because I can just remember. Oh, I made a stew once but he cut the meat. He was concerned about me cutting the meat. I said no, 'I've got to learn. I've got to be independent.' " I admired her perseverance to stay active and independent. I wondered why Mr. Team wanted to discourage her, didn't he realize how much he relied on her following his falls? Perhaps he hoped he would never fall again.

Mrs. Team also verbalized concern over his use of her blindness as something she should exploit. His identification of her visual impairment to complete strangers caused her pain and humiliation. He couldn't understand why she didn't want everybody to know. I got the distinct impression that things would be far different if the situation was reversed.

I was aware that when Mrs. Team was required to caregive, the burden for her was immense. However, I don't believe it still played a factor in her feeling burdened, nor do I believe it contributed to their marital discord. I wondered if her spouse might feel burdened because for the rest of the in between his falls, he looked after her. If anything, I thought a feeling of reciprocity might enable Mr. Team to cope better with the caregiving role, as she had been there for him in the past (Goodman, 1999). But Mr. Team did not have difficulty with the role transition and in fact, seemed to adapt to it very well. Mrs. Team said he had cared for his mother and siblings in the past. His reaction is not unusual and is supported in the literature by the work of Archbold, Stewart, Greenlick and Harvath (1990) who found preparedness ameliorated some of the caregiver strain.

The Readers

Although she had been married for many years, Mrs. Reader did not have the kind of marital relationship I thought she had when I met her for our first visit. It was only during our second and of course our third visit that she opened up more, and I began to understand the situation she was in. She spoke about the loving, humorous man she married, her "best friend", and how he changed after his breakdown into a man she didn't care to know. She stayed with him, even after her children were grown and had children of their own. She told me she stays with him now out of a sense of duty and obligation. She mentioned a time when she was suffering from severe and painful bursitis, and unable to complete her usual tasks without difficulty. Working at the time, she said her husband, although capable, did not offer to help her in any way to relieve some of the burden she was under. She said that she felt that unless she was actively bleeding, he felt she did not need his help, and did not validate the pain and suffering that she was feeling. Now, remembering these past incidences, instead of validating her caregiving, it made her question why she was continuing to give to a man who had stopped giving back many years ago. "Understanding reciprocity in marriage is particularly relevant for older couples as one or the other may face illness and dependency which can disrupt marital balance when one spouse becomes a caregiver for the other." (Goodman, 1999, p.341).

Intertwined throughout Mrs. Readers stories are words common to the burden literature. Her stated feelings of exhaustion and inability to cope speak to the caregiver who is burned out (Ade-Ridder & Kaplan, 1993). Her fear that her spouse might go AMA spoke to her inability to cope with his physical decline. Decline in self care abilities of the care receiver and difficulty coping with the role changes of the caregiver are common reasons for institutionalization (Chenier, 1997). Because Mr. Reader was mentally competent, his spouse knew he would never consent to going to a long-term care facility, she also knew she could no longer cope on her own. She said that after he came home she aggressively sought assistance from her family physician who ordered a home care assessment and soon following had caregivers in to help her. In the beginning he was just requiring someone to help him get up and washed and dressed in the morning but after Christmas his condition deteriorated requiring assistance in the evening as well. Studies have shown that delay in institutionalization can occur with the right amount of home care supplement (Gaynor, 1990). Right now Mrs. Reader was just about receiving the right amount. Coupled with her new found ability to leave him on his own for some respite, Mrs. Reader was coping with her marriage and role strain by taking now, "day by day".

The Campers

The marital discord I was privy to during our visits revolved around Mr. Camper's frustration at not getting things done both in the house and garden. He was anxious to be out looking after his yard and garden but also felt like he needed to be inside to settle his wife for the day, before he could venture out. I could tell, during the second visit that there was a bit of a battle regarding this. She was certain that she could manage without him, and he didn't want to take any chances. He felt tied down and restless, becoming increasingly more frustrated the further behind he got.

All of the co-participants, except for the Ables, had issues with their spouses possibly contributing to caregiving difficulties. Mrs. Team was caregiving a spouse after his falls who did not like to relinquish control. Mrs. Reader described her husband as not the same man she had married since his breakdown. She struggled with whether she was providing care out of duty and obligation rather than out of love and commitment. Mr. Camper repeatedly expressed feeling tied down, resenting his wife for sleeping late. The impression of dissatisfaction with caregiving from a marital relationship perspective for these three caregivers gives credence to the work of Goodman (1999). Goodman describes the need for creating a shared perspective with their marriage. Citing Duck's (1994) work, Goodman describes that where meanings are created jointly, "the shared meanings serve to strengthen and maintain the couple.... Incongruent couples are at risk as a result of little shared meaning about the quality of married life." (p.351) In her study of spouses in long term marriages, Goodman (1999) discovered that spouses who "give more" that is those who feel like they are contributing above that of their spouse, "offer the least positive descriptions of their marriages." (p.352) The women in her study emphasized areas focusing on relationship as most important whereas the men focused on areas of control. Mr. Camper was also feeling multiple role strain, having his regular chores to attend to, he now had things inside the house that required his attention that he was disgruntled at having to handle. One such chore was the grocery shopping. The frustrations at falling behind, having things left on the "back burner" indefinitely, and the lack of something tangible to pin point for the reason for his wife's falls was more than enough reason to cause Mr. Camper to be frustrated and angry. It is understandable that he was feeling this role strain. Fortunately for him, this strain was somewhat mediated over the enormous assistance provided to the couple by their young, unmarried daughter.

Supportive Relationships

Despite my familiarity with senior caregiving situations, both in the literature and in my clinical practice in acute care, I was still amazed at the support given to two of the couples in the study in particular, the Teams and the Campers. It is my professional opinion that these couples would not be able to live independently, together, were it not for the help they received from their children. Similar to research done on caregiving support, daughters were found in this study to play an important role, sometimes taking over for the spouse as caregiver. However, this study also found that sons may be more involved with caregiving tasks then what one might expect. This is important because a bias may form and assumptions may be made that the daughters or daughter-in –law are the secondary caregiver to the spouse who is caregiving, when in fact the sons may be doing as much or more in some cases. In this study both sons and daughters were very involved in helping their parents.

The Ables

Although the Ables did not require support from their children to help them stay independent, they did enjoy a close relationship that Mr. Ables called supportive. Mr. Ables was out at his daughter's place the night before our second visit since he was "batching it".

The Teams

Although the concept of support, and the ability of certain types of support to sustain independence, has been well documented, I was nevertheless surprised at how well the Teams, as disabled as they were, were doing. Between their tag-team style of caregiving for each other, and the significant help given to them by their children, this couple was not only surviving, they seemed to be thriving. I felt strongly, particularly with this vulnerable couple, if it were not for their children, they would not be able to maintain their independent living. The support they received was extraordinary. I was gradually introduced to her entire immediate family throughout our visits, through Mrs. Teams' stories, because the family was so integral to their lives.

When Mr. Team fell and broke his pelvis, their son came and picked Mrs. Team up at the beauty parlor. Their daughter was able to get Mr. Team readmitted to the hospital after he was accidentally discharged with a broken pelvis. In too much pain to tolerate another trip to the hospital Mr. and Mrs. Team spent the night at home joined by one son, one daughter, and a five-year-old grandchild. Because of Mrs. Teams' visual impairment, and Mr. Team's difficulty with mobilizing following the severe fall, the adult children were called upon to find them new accommodations. Not only did they find them somewhere to live; one son measured everything out and told them what furniture was going to where. "All the boys took a day off work and they just moved us in. The girls unpacked and put stuff in the kitchen cupboards and that was it."

Following their move, the Teams relied on their children to do the weekly grocery shopping. "They take turns so it's somebody's turn every three weeks and he just phones them a list. Our family has been just wondrous. Even my daughter with her four children; twelve, ten and then the twins that are six. We've got one daughter here and two sons." Sons were called to take Mrs. Team to various appointments and outings. Mrs. Team never hesitated to call her daughter that lives several hundred kilometers away to come when she was needed. Mrs. Team described one example of when she went to live with her daughter for six weeks when her daughter came home with the twins. She felt that the help they were now receiving was a reciprocation of the help she had given to them and the other children in the past. She said it was different for her husband who found accepting others assistance difficult even when it was necessary. "The kids will say, 'well dad, can I help you?' 'I can do it, just leave me alone. I can manage.' Less accepting of

assistance, Mr. Team tried to do as much as he could, and only then would he ask for assistance. Being a very proud man, help had to be received by him on his own terms, not just when it was offered.

Mrs. Team also continued to occasionally visit with old friends, who would pick her up and take her out. During our visits, she mentioned her CNIB volunteer/friend several times and several photographs of Mrs. Teams contain pictures of this woman. The volunteer was very encouraging in motivating Mrs. Team to do more things that she used to. "She's at me all the time, 'Now you could do this.' She says, 'You should be able to do everything you did before you lost your sight.' I was glad that this special network existed and that Mrs. Teams received support for her visual disability.

Both Mr. and Mrs. Team contributed to the running of their household to the best of their abilities, Mrs. Team doing dishes, laundry and ironing. Sharing together the meal preparation, he managing the finances in the typical gender traditional roles. They received help twice a month with dusting and vacuuming and Mrs. Team says she has a wonderful daughter who monitors and takes care of the finger- prints from the walls where Mr. Teams journey's around the apartment can be mapped. Contrary to the finding in Ethel Shanus' (1979) seminal article discussing social support, in which she reports that when spouses needed help, paid caregivers were the next in line to call, followed by children. Perhaps since the Teams did not require personal care they did not need the services of paid caregivers except for what they received for housekeeping once every one or two weeks. Family was whom they could count on to. The Teams clearly showed that despite having the odds against them, precarious couples can live independently with extensive family support.

The Readers

For Mrs. Reader, the support she required was more formal as she needed help assisting her debilitated spouse with everything from getting out of bed in the morning to bathing, dressing, and grooming to mobilizing and medication administration. After her spouse signed himself out against medical advise from the rehabilitation hospital, Mrs. Reader assertively sought assistance, first from her family doctor, who then put community care in contact with her. She now receives twice daily assistance caring for her spouse as well as once weekly bathing. Recognizing her need for regular respite, Mrs. Reader had a three-week holiday employing privately, twenty-four hour home care for her spouse while she was away. Unfortunately others cannot afford this respite on their fixed or limited income. The Readers, similar to the Ables, do not rely on their son or daughter for any support other than social, which is not meant to minimize its importance.

Mrs. Reader gets regular social support from her children as she continues to meet her daughter for lunch once a week and her son continues to visit them both at the house at least once a week. During her time of worry when Mr. Reader was hospitalized, she talked about the strength she would get just by having them by her side, supporting her at the hospital to help convince her spouse to stay in and get better. "I need to have daughter here (motioning to her right side), son here (motioning to her left side), strengthening my spine and saying, "No, you're not coming home." She said she didn't want to burden her children with her problems but was sure they would support her and help her. I wonder now if she felt betrayed by her son after he picked up Mr. Reader when he left AMA.

The Campers

Mr. Campers' caregiving situation too, highlighted the importance of family members as informal helpers. Mr. Camper, although the caregiver, received substantial daily support from his unmarried daughter, as well as outside assistance from external agencies. "Lilly", as I had come to know of her, came to the Campers daily after she finished work to finish off the supper meal preparation and help with the clean up. The youngest of two daughters, Lilly helped with everything from grocery shopping to cleaning up after the cleaning lady, as it was never quite done to Mrs. Campers' satisfaction. "I don't know what I would do without L because she does the banking and she comes in at night and helps make supper and cleans up and…" I interrupted in wonder asking if this occurred every night. "Monday to Friday and she comes on Sunday. Saturday, we usually go out for lunch." I inquired if their other daughter was as helpful as the one they'd been extolling me about. Mrs. Camper lamented: "Not like she used to be. She used to do a lot for me but since she's been living with this guy, she doesn't do too much I sometimes think she could do more for me but I won't ask her anymore. I figure if she doesn't want to do it willingly, I mean, I never have to ask L to do anything for me, she just knows what needs to be done and she does it. That's like B. He came home just to give everybody a rest and he's been here for almost a month."

I was happy they received so much freely given family support. I worried what would happen if Lilly suddenly got a significant other. I was sure they, like the Teams, would not be able to live independently, together, without the support of their children. I wondered what type of assistance Ben would offer would he be involved in the more traditional gender based activities such as yard work and repairs or would he continue on where sister left off. Ben said that he was doing everything from watering the plants to laundry and sewing. I was happy that he was so capable, his sister might get a well-deserved break, or at least a lessening of her load. While Ben was here he also intended to assist his mother in finding a new family physician. They had lost all respect for the one they had currently, because of some poor past practices, and unsatisfied concerns regarding the seven pills she took, daily, some twice daily. Ben alluded to other things that needed taking care of but did not expand on this further. Because of Mrs. Campers' severe rheumatoid arthritis, she had been getting home care assistance, three hours a week, for the last ten years. She was not impressed with the quality of work they performed at her house and voiced her dissatisfaction to me several times. A bath lift had been installed to assist caregivers to help her bathe once a week. She say's she can't wait that long until the next shampoo, so often Lilly will wash it again for her.

The Campers had one more area of really strong support that was not the same for the other couples. Their neighbors played a supportive role that was not described by the others, of their current neighbors. Both Mrs. Team and Mrs. Reader kept in touch with previous neighbors that they had known many years ago. Mr. Ables and Mr. Camper had lived in their houses approximately the same length of time, yet Mr. Ables did not speak at all about his neighbors, whereas Mr. and Mrs. Camper had endless stories to share about theirs.

Interestingly, although the literature supports the notion that women are the vast majority of caregivers (Fengler & Goodrich, 1979), in this study, sons were very much a needed part of the caregiving team.

CHAPTER SIX: IMPLICATIONS FOR NURSING

Implications for Clinical Practice

Because nurses practice in settings where they are in contact with senior caregivers, they are in an ideal position to assess and facilitate role performance of the caregiving process. In doing so, nurses can meet the caregivers unique needs that caregivers have as this study demonstrates. In doing so, this enables them to better help their spouses and perhaps avoid premature institutionalization (Swanson, Jensen, Specht, Johnson, Maas, & Saylor 1997; Browning and Schwirian, 1994; Chenier, 1997).

The assessment of the caregivers' needs by the acute care nurse is equally as important as assessing the patients needs before discharge home. This should be done early in the caregiving relationship, so resources can be discussed thereby mediating some of the damage if premature discharge occurs or, the patient signs himself out as can happen. This way the caregiver is not left without much needed support when their spouse is back at home. Nurses must advocate on the part of both the patient and caregiver to avoid premature discharge, assuring patients return home mobilizing and caring for themselves the same, if not better then when they came in. As this study demonstrates, nurses could be discharging their patient's back to caregivers that are exhausted, disabled, resentful and frustrated. As well, it is important that the health care provider hear the caregivers' stories separate from their spouse, because as this study demonstrates, spouses may to hold back their true feelings when in the presence of their spouse.

Nurses should encourage caregivers to tell their stories, listening to their knowledge and competency as it is shared. Acknowledging their contributions to their spouses, nurses can validate and empower the caregivers who may be feeling powerless as things move beyond their expertise or domain of knowledge and control. "Caregivers must be recognized for their unique knowledge of the care receiver's preferences, values, needs, and life history." (Rutman, 1996, p.107)

Recognizing the caregiver and the care receiver as a dyad is another important element to providing holistic care to these elderly couples and one that is echoed in the literature (Rutman, 1996; Chenier, 1997). Too often the caregiver is unaccounted for by the health care team in acute care. The caregiver may be absent after the spouses admission. This may be due in part to the relief the caregiver may feel at having someone else caring for their loved one, leaving them opportunity for activities otherwise unattainable without the respite. The caregiver may also feel a sense of inadequacy once in the high tech intimidating hospital environment. The nurse must recognize that the caregiver may be feeling burnt out or intimidated and may be absent or keeping to the background, their valuable knowledge remaining hidden until a caring health professional makes the effort to bridge this gap. The difficulties the Campers and the Teams experienced with the health care system serves to highlight the importance of the nurse to hear and advocate on the part of the caregiving dyad.

Respite care may be needed to allow the burnt out caregiver time to rejuvenate. Help may be needed to plan regular respite for these caregivers for the future.

Communication between the hospital nurse and the community care nurse needs to occur. The communication must be clear and accurate, reflecting the issues that the couple are dealing with. In this way care can continue and well-developed care plans can be reinforced (Browning & Schwirian, 1994). This would have helped Mrs. Reader to feel less like "a nag" because the nurse would be assessing for compliance when she made her visits and could perhaps re-motivate where motivation has started to flag.

Nurses practicing in clinical settings must be prepared to advocate for senior couples to prevent discharge back home if the patient has not yet reached their pre-admission level of functioning (Browning & Schwirian, 1994). Patients must be physically and mentally able to resume self-care or care with previous level of assistance. As this study shows, caregivers are often already overburdened and are unable to tolerate further decline in their spouse's functional capacity, either mentally or physically.

Ongoing collaborative assessment of the couple, by the community health nurses and other disciplines such as the physiotherapist can evaluate at the earliest point, which intervention could be successful to keep the spouse home. Respite care made an enormous difference to Mrs. Reader allowing her to carry on with renewed vigor. Similar results have been documented in caregiving studies (Archbold, Stewart, Greenlick, & Harvath, 1990). Counseling and support groups should also be available with "adult minding" available so the caregiver can bring their spouse.

Implications for Research

Using two relatively new methods of research is beneficial in the development and the furthering of knowledge and theory. "Nursing scholars are persons in a constant and common search for understanding the content of nursing.... Nursing cannot occur from the exterior. It only occurs through entering the world of the person(s) being cared for, understanding that world and the calls emerging from it, and responding to them" (Boykin

& Schoenhofer, 1991, p.247). Using 'Visit' as a method of relational research enables nurses to communicate with caregivers by hearing their stories. Through repeated visits, the narrational relationship develops allowing the researcher and co-participant to build trust and understanding. Supplemented by the use of photography, nurses can visualize the meaning that the caregivers attribute to their experience. A symbol used to highlight things of importance to them.

Implications for Nursing Education

This study demonstrates the importance of nursing education directed at the aged. Assumptions that women will naturally assume caregiving roles needs to be challenged as was demonstrated by some of the women in this study. As our population ages, more couple will find themselves in similar situations as the participants reported here. It is essential that nurses be taught the benefits of hearing the narratives, listening for the individuals unique needs and issues. Learning about and practicing family and couple interviewing will assist the student in the realities of the caregiving dyad and aid in understanding the importance of listening also to the support systems utilized by both the patient and the caregiver.

Nurses must also be taught the complexities of aged care in the community, resources available, as well as support and government services. Physical as well as social, psychological and cultural assessment of the elderly combining a knowledge base of normal versus abnormal aging should also be requirement of nurses in the future and included in the curriculum.

Conclusion

This study was designed to explore the experience of caregivers, caring for spouses at risk for falls. A qualitative approach using two relatively new methods, 'Visit' and interpretive photography, was used. Using new methods helps to expand nursing knowledge and lends further credibility to the methods through their repeated use. The visits are the co-created stories that evolved out of the narrational relationship that develops over time between the researcher and co-participant. Through the use of photographs taken by the co-participants, researcher and expert together entered into the narrational dialogue, weaving the unique and intricate meanings, each individual's experience had. The spouses explored what they felt encompassed their experience in caring for their spouse. Welcomed into their homes, I was touched by the situations and issues these courageous couples faced. From their stories the important messages for learning were unveiled. The first was the significance of the fall. The significance of their spouse's fall was interpreted differently by each caregiver. From a warning sign to be careful, to a symbol of the end to life as "just a spouse", the caregivers described the significance their spouses' fall(s) had for them. Each spouse also demonstrated incredible self- sacrifice, sometimes putting their own health in jeopardy to help their partner. Marital discord was also present for three of the couples. As care needs increased and caregivers became more fatigued, they were less and less able to tolerate the stress of constant care. For one caregiver, a vacation was all she needed to invigorate her spirit again. The final message was that of support. In this study sons were very instrumental in assisting their parents to remain independent, a resource that may not generally be tapped due to misconceptions about their level of participation. Using the photographs in addition to the narratives helped to make the unspoken, spoken and the invisible, visible. The outcome is a grounding of nursing care that is based on expanded understanding of older adults.

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