

**EXPLORING PHYSICAL PAIN AND INJURIES IN
INFORMAL CAREGIVERS TO OLDER ADULTS**

by

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ABSTRACT

Previous studies document positive and negative effects of informal caregiving on the caregiver's physical and mental health. Although injuries are highly prevalent in professional home care workers, they have not been fully examined in informal caregivers. This study has explored physical pain and injuries in informal caregivers to frail older adults using the grounded theory approach and symbolic interactionism theoretical background. In-depth interviews have been conducted with twenty primary caregivers. Injuries in study participants included muscle and back strains, falls, sprained ankles, twisted knees, a broken wrist, a dislocated shoulder, and burns and bruises. Female spousal caregivers were especially vulnerable to physical pain and injury. A substantive theory was developed, relating to the social process of "attenuating the caregiver's well-being while accentuating the care recipient's well-being in the course of informal care provision." This will provide a useful conceptual framework for future studies and caregiver interventions.

Keywords: informal; caregiving; health; effects; injury; pain

Subject Terms: caregivers; Canada; health; hygiene

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CHAPTER 1: INTRODUCTION

Informal caregiving can be defined as the continuous process of providing care to an individual in need by a non-professional, unpaid person, usually a family member or a friend. Typically, such care entails companionship, assistance with activities of daily living (dressing, grooming, meal preparation, etc.) and instrumental activities of daily living (shopping, transportation, housekeeping, etc.). Informal caregivers may also assist their care recipients with personal care, such as bathing or washing. In the early period, gerontological research focused primarily on the elderly care recipients and their health and well-being. In the 1970s and early 1980s, the first anecdotal descriptions of family caregivers' experiences emerged. Gradually, it became apparent that this is an important population to study. The significant role of family members in eldercare has been acknowledged and numerous studies have shed light on the processes and outcomes of providing care to an elderly relative.

Caregiving has indeed become a common experience for Canadian families. Some authors estimate that as much as 90% of care provision to seniors in Canada is informal (Angus, Auer, Cloutier & Albert, 1995, as cited in Keating et al., 1999). Keating et al. (1999) suggest that nearly one in eight adult Canadians provide care to an individual with chronic health problems, usually an older parent. Indeed, the role of informal caregivers in eldercare is essential. However, some authors warn us that informal resources for eldercare may be diminishing in our changing society.

For example, Noelker (2001) notes that there is increasing concern about the ability of families and friends to continue providing care to older adults with chronic health conditions. This is due to socio-demographic changes in recent decades, including increasing proportions of older populations, changes in family structure such as smaller family size, higher divorce rates and the greater geographical dispersion of families. Negative effects of caregiving on caregivers' physical and mental health may further impede the ability of families to provide for their frail elderly relatives. Therefore, maintaining the physical and mental health of informal caregivers is crucial in sustaining adequate eldercare.

Previous studies demonstrate that informal caregiving can influence the individual's overall well-being. Accounts of negative experiences in the informal caregiving literature encompass family disruptions as a consequence of role changes, role overload, and ambiguity and family conflicts. Respondents complain of psychological stress, physical fatigue, social isolation, financial problems and legal problems as a result of the increasing mental and physical incompetence of the care recipient (Orzcek et al., 2001). Schofield et al. (1998) also note that caregivers often feel constrained and limited in their freedom and activities. They report lower life satisfaction when compared to non-caregivers. Sleeping problems are also common, resulting in extreme fatigue and compromised health.

Providing care to a frail older adult is demanding and challenging but it can also bring positive experiences, such as improved self-esteem, new acquired skills or a better relationship with the care recipient. For example, participants in a longitudinal study by Schofield et al. (1998) express satisfaction with the caregiving role, such as pride in

seeing the care recipient accomplish tasks, enhanced confidence in dealing with others and reassurance that the recipient was getting proper care. Similarly, Orzeck et al. (2001) report feelings of love, reciprocity, filial duty and fulfilment linked to informal caregiving experiences. These positive experiences may alleviate the negative effects of providing care on the caregiver's health. Pinquart and Sörensen (2003) argue, that caregivers derive benefits from the caregiving experience. Positive aspects of providing care alleviate their feelings of burden. Those who discover a new meaningful and satisfying role in helping their loved one may find caregiving less stressful. Improved self-esteem and new skills can be useful in dealing with stressful and challenging caregiving situations that could otherwise lead to potential injuries.

One issue that has not yet been fully explored in the caregiving literature relates to injuries incurred by informal caregivers and their experience of physical pain. Numerous studies examine the negative effects of care provision on the caregiver's mental and physical health. However, our understanding of potential injuries and physical pain in informal caregivers is very limited. Do informal caregivers get injured in the course of helping their elderly relatives? How do injuries occur in informal care settings? What are their consequences in the lives of the care recipient and the caregiver? How is physical pain experienced in the context of informal care provision? These are a few unanswered questions in the caregiving literature. This comprehensive understanding of injury and pain in informal caregivers is critical in designing caregiver support programs and interventions.

Alarmingly, previous research documents that injuries are a significant threat to the health of professional caregivers. For example, the Occupational Health & Safety

Agency for Healthcare in B.C. [OHSAH] (2005) reports that health care workers are at the highest risk of getting injured when compared to other sectors. Injuries are particularly prevalent in community health workers. Professional caregivers accounted for 60% of serious injuries in B.C. in 2003 with the main source of injuries being muscle strain accidents from pushing, pulling, lifting and carrying (Network of Centres of Excellence [NCE], 2005).

The statistics cited above show that care provision in a home environment with inadequate equipment for lifting and transitioning can be hazardous for professional caregivers. Informal caregivers often perform the same type of tasks as professional home support workers, such as transferring, bathing, dressing, grooming, and meal preparation and household duties. They typically lack professional training and knowledge of safe “patient” transferring techniques. Their tasks may be physically demanding without appropriate assistive devices (mechanical lifts, etc.). In situations in which a two-person transfer would be legally required in a healthcare setting, an informal caregiver usually struggles on his or her own. Therefore, both the caregiver and the care recipient are at a risk for injury.

Unlike professional health care workers, informal caregivers work from home and their responsibilities are not considered employment for which they obtain insurance coverage. Conversely, injuries to paid homecare employees are reported and compensated by the Worker’s Compensation Board. The effects of physical pain and injuries on the caregiver and care recipient may be tremendous. Among professional workers, injury claims lead to periods of work absence and the increased utilization of health care (OHSAH, 2005). In informal caregiving situations, an injury could possibly

lead to decreased ability or even an inability to provide care. The caregiver's health and functional status may be adversely affected. This could initiate the need to rely on formal systems and result in the premature institutionalization of the care recipient, increased service use by the caregiver and potential work absence.

1.1 Study Purpose and Rationale

The contribution of family members and other informal caregivers in caring for older adults is vital in our society. It would be impossible for the formal service systems to replace or substitute the role of informal caregivers in an adequate way. Although formal long-term care plays an important role in elder care, it lacks the personal, familiar and emotional aspects found in informal care provision so important for the older adults' quality of life. Aging at home in a familiar and meaningful environment with connection to close relatives is crucial for quality of life and overall well-being.

Having said that, formal service systems can hardly rely on informal caregivers without adequately supporting them in their challenging and demanding role. Informal caregivers' health is imperative for effective eldercare in Canada. Caregivers in better physical and mental health will be more likely to provide quality care to their family members or friends. On the other hand, informal caregivers suffering from compromised health will rely more on formal systems both for their own health needs and for the needs of their care recipients. Physical pain and injury in informal caregivers may result in their hospitalisation and short-term or long-term inability to provide care. This could consequently lead to the unnecessary institutionalisation of the care recipient.

Furthermore, the caregiver may suffer from long-term effects of injury and thus may himself or herself prematurely require care.

In conclusion, this study of physical pain and injuries in informal caregivers addresses a significant gap in caregiving literature and it is a first step in drawing attention to these issues in gerontological research and health policies. The goal of this study is to explore the context in which these phenomena occur in informal caregivers and to yield an improved understanding of caregivers' health in the course of providing care. Practical implications of this research will be useful in designing and implementing caregiver interventions and in preventing injuries and physical pain in those who dedicate their time, energy, skills and their own health in providing for their elderly family members.

The secondary goal of this study is the generation of a theoretical framework that will be useful in the development of caregiver interventions and injury prevention strategies. Recommendations to guide policy in reducing caregiver injury may help avoid unnecessary physician visits, hospitalization and institutionalisation, which can save health care costs. Finally, findings from this study will provide groundwork for future investigation of injuries and physical pain in informal caregivers.

CHAPTER 2: STUDY OUTLINE

This study focuses on "negative" experiences, specifically physical pain and injury. However, positive effects and their role in the experience and meaning of physical pain and injury in informal caregivers are also examined. Although previous research is sparse in this area, it could be possible that informal caregivers who are satisfied with their role may feel less burdened and stressed. As a result, they could be less prone to injury. Positive aspects of care provision can possibly moderate the experience of physical pain and suffering and alter their meaning for the individual.

A qualitative approach based on grounded theory is employed. Grounded theory is particularly well-suited for research studies aimed at exploring new areas. It is also extremely valuable for understanding the lived experience of persons affected by a certain phenomenon (Creswell, 1998; Denzin & Lincoln, 1994; Denscombe, 2003). In this way, the role of a number of contextual factors in the experience of physical pain or injuries in informal caregivers can be better conceptualised and understood. These include, for example, the physical home environment in which care is provided, the caregiver and care recipient relationship, positive and negative aspects of care provision as perceived by the caregiver, caregiver coping strategies and available and utilized resources (social, emotional, financial and material, services, etc.).

2.1 Research Question and Research Sub-Areas

Given the gap in the literature with respect to injuries in informal caregivers, one overarching research question guides this study: “What is the context in which physical pain and injuries are experienced in informal caregivers for older adults?” The primary research question was subdivided into six sub-areas. This was based on a thorough literature review, in which gaps in caregiving research were identified. Research sub-areas were developed as logical thematic areas relevant to an initial contextual analysis of this under-researched topic. These sub-areas guided the initial data collection and were continuously modified. Themes and concepts emerging in data collection and analysis were constantly compared to previously collected data, literature and the developing theory.

1) The caregiving situation and physical pain and injuries in informal caregivers.

What is the caregiving situation in which injuries and pain are experienced (e.g. living arrangement, physical environment, caregiver and care recipient characteristics, their relationship, etc.)? What types of injuries or pain are experienced? How do these physical discomforts occur? How do caregivers perceive injury and pain?

2) The consequences of physical pain and injuries to informal caregivers

Do injuries and pain affect caregivers’ and care recipients’ lives? What are the consequences of injury and pain in informal caregivers?

3) Problematic aspects of the caregiving experience.

What aspects of the caregiving experience are deemed especially stressful and challenging? What are potential injury triggers?

4) Positive aspects of the caregiving experience and their role in explaining physical pain and injury.

What are the rewards or positive aspects of caregiving that assist the caregiver in dealing with the challenges of care provision? Do positive experiences moderate physical pain and bring more positive meaning to injury and suffering?

5) Caregiver coping strategies.

How do caregivers deal with negative aspects of care provision? What strategies are they using (self-care, leisure, medication, substance use/abuse, social outlets, meditation or spiritual coping, etc.)? How do they deal with physical pain? How do they manage pain?

6) Personal, social, economic and community resources utilized by informal caregivers in dealing with physical discomforts and preventing injuries.

Who helps primary caregivers deal with potential physical discomforts? What other resources (both formal and informal) do informal caregivers utilize? What seems to help? What does not seem to help?

CHAPTER 3: THEORETICAL FRAMEWORK

This study is designed as an initial investigation of a rather unrecognised phenomenon within the informal caregiving context. Previous studies on this topic are sparse. Moreover, a framework that is sensitive for capturing context was required for the purpose of this study. This framework also emphasises the subjective nature of physical pain and injury as experienced by each individual caregiver. Therefore, qualitative research methods, using grounded theory approach, have been employed. Grounded theory stems from the theoretical concepts of *symbolic interactionism*, a sociological paradigm developed in the 1920s-1950s. Symbolic interactionism has been applied as a theoretical background for this study. This chapter will summarize the main concepts underlying symbolic interactionism and grounded theory. The suitability of these approaches in exploring the experience of injury and pain in informal caregivers will be discussed.

3.1 Symbolic Interactionism

The grounded theory approach derives from symbolic interactionism, a well-established sociological paradigm that focuses on the processes of creating meaning in everyday life (Blumer, 1969). Blumer's work centred on the ways, in which individuals take control of their lives as “acting people” in a society of “complex ongoing activity” (Adams & Sydie, 2002).

Symbolic interactionism conceptualised the dynamic processes of interpersonal relating in which meaning is created in social interaction (Fassinger, 2005). Denscombe (2003, p.113-114) defines symbolic interactionism as a “form of social research that focuses on the way that participants in social settings make sense of things through their interaction with other participants in the setting.” The subjective nature of phenomena as experienced by individual social actors is emphasized. The world of experience is viewed as a world composed of meanings that are shaped by context (Gubrium & Holstein, 1999). In summary,

Human beings act towards things on the basis of the meaning things have for them. The meaning of such things is derived from, or arises out of, the social interaction one has with one’s fellows. These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, 1969, p. 2).

3.2 Informal Caregiving From the Symbolic Interactionism Perspective

Symbolic interactionism provides a valuable framework for interpreting the experiences of informal caregivers. It captures the subjective nature of the experience and meaning of injury and pain in individual caregivers. Jeon (2004) maintains that “meaning” is the core element in understanding human behaviour, interactions and social processes from the symbolic interactionism perspective. In order to gain a full understanding of social process, researchers are required to “grasp” the meanings that are experienced by the participants within a particular context (Jeon, 2004).

The context of the caregiving scenario plays a significant role in the experience of injuries and physical pain in informal caregivers. This involves, for example, the physical environment of the home, where care is provided, the family situation and dynamics and

financial circumstances. The physical and mental health of both the caregiver and the care recipient must be taken into account. The social environment and resources, recent significant events experienced by the caregiver and the care recipient, their relationship and many other factors at the *micro*, *meso* and *macro* level of the environment should be examined.

The concept of *joint action* described by Blumer in 1969 is particularly pertinent to the caregiving experience. In the process of joint action, individuals take into account others in the situation as well as the effect that one's own actions will have on others (Perry, 2002). This furthers the importance of exploring caregiving experiences within the specific context, where not only the carer but his or her significant others and social influences are considered.

Symbolic interactionism emphasizes the participant's point of view. Research conclusions and concepts deduced from a symbolic interactionism perspective embrace the individual's experience and the meanings attached to the explored phenomena within specific contexts. This theoretical framework fully facilitates the practicality and usability criterion that guided this study. Hence, symbolic interactionism as a theoretical framework and grounded theory as a methodological approach fully accommodate the purpose and nature of this study.

In summary, symbolic interactionism perspective guided this study in the sense of developing research questions and sub-areas that focus on the context in which injuries and physical pain occur in informal caregivers. Moreover, individual differences in the experience of these phenomena were emphasized, as well as the meaning that individual caregivers attach to them. However, this perspective was not strictly employed as a

superior theory governing this investigation. Symbolic interactionism provided guidance in formulating initial questions. As previously discussed, these were considered open to modification in the dynamic process of data collection and immediate analysis.

Therefore, using symbolic interactionism as a theoretical background did not constitute a pre-conceived theory in explaining the studied phenomena.

3.3 Grounded Theory Approach

Glaser and Strauss introduced grounded theory in their 1967 publication *The Discovery of Grounded Theory*. In this classic work, these authors emphasize the need to generate theories by a systematic analysis of empirical data (Creswell, 1998; Denscombe, 2003; Fassinger, 2005; Strauss & Corbin, 1994). Denscombe (2003) characterizes this approach as one that directly challenges the practice of theorizing at a high level of abstraction and subsequently undergoing empirical research to test the theory. As Creswell (1998) notes, Glaser and Strauss hold that theories should be “grounded” in data from the field, in the actions, interactions and social processes of persons experiencing by a certain phenomenon. According to Cutcliffe (2000), grounded theorists interrogate meanings created in social relationships in an attempt to discover how groups of people define their realities based on their understanding of interpersonal interactions. This is particularly relevant in health research because

[g]rounded theory tells us what is going on, tells us how to account for the participants’ main concerns, and reveals access variables that allow for incremental change. (Glasser, 1999, as cited in Denscombe, 2003, p. 110)

The ultimate research goal in a grounded theory approach is the development of a theory that will be anchored in the empirical data, rather than testing of preconceived

theories and hypotheses. The conceptual framework and substantive theory emerge in the process of data collection and analyses. Fassinger (2005) describes grounded theory as follows:

Theory is derived inductively through an iterative, concurrent process of data collection, coding, conceptualizing, and theorizing, wherein new data are constantly compared to emerging concepts until no new themes, categories, or relationships are being discovered, at which point the properties of, and relationship among, constructs are specified in the form of a substantive theory about the social behaviour under investigation (Fassinger, 2005, p. 156).

3.4 Open or Empty Mind?

Interpretations and applications of grounded theory approach differ among qualitative researchers. The literature shows many variations in methods, making sense of the data, and drawing research conclusions. The founders of grounded theory, Glaser and Strauss, have since suggested different paths in developing the theory and its methodological guidelines. Glaser maintained that the “true” grounded theory standpoint dictates approaching the field of study without any precise research questions or research problems. The application of theoretical background knowledge about the researched area was to be considered a constraint or even “contamination” of the emerging theory (Kelle, 2005). Strauss, in cooperation with Corbin, on the other hand, described a somewhat more guided process of generating theory. Their stance, according to Kelle (2005), allows for accessing the study area and coding data with a theoretical perspective in mind.

The extent to which previous theories or concepts are incorporated into the initial stage of grounded theory research varies significantly among studies. Most grounded theorists favour minimal familiarity with literature and theories in the early stages of

conceptualizing the study and collecting data. Denscombe (2003), for example, interprets grounded theory approach as “embarking on a route of discovery.” Researchers are required to “bracket out” any preconceived theories or expectations, in order to maintain a fresh and open-minded approach in their study of a certain phenomenon (Glaser & Strauss, 1967). This implies being informed about an area, or being aware of previous theories that might apply, but avoiding their use to make sense of the data (Denscombe, 2003). Fassinger (2005) points out that the researcher needs to maintain a delicate balance between sufficient knowledge for effective sampling and data collection, and circumscribing the investigation by preordained constructs and limited expectations.

This study was predominantly guided by Strauss and Corbin’s standpoint and their concept of *coding paradigm*, which is further discussed in Chapter Five. Kelle (2005) maintains that

Strauss’ and Corbin’s concept of a ‘coding paradigm’ serves to explicate the construction of theoretical framework necessary for the development of empirically grounded categories in a much more user-friendly way. By drawing on this concept, researchers with limited experience in the application of theoretical knowledge can use Grounded Theory methodology without taking the risk of drowning in the data (Kelle, 2005, p. 17).

Kelle (2005) therefore recommends Strauss and Corbin’s approach to novice researchers who seek clear guidance on structuring data material. However, I will also refer to some of the original ideas in Glaser and Strauss’ work. As Jeon (2004) argues, one cannot separate “Glaserian” and “Straussian” views as being completely different. Both authors claim that their recent elaborations of grounded theory derive from and incorporate the original concepts.

I chose to embark on the research journey after a thorough review of the caregiving literature. I was thus fairly informed about various aspects of informal caregiving experience from the diverse standpoints of previous studies. However, following the criterion of an “open mind,” I merely used precedent knowledge of informal caregiving in order to identify gaps in the literature or contradictory findings and concepts. This guided my choice of research questions. I considered theoretical frameworks and conclusions from previous research as provisional and subject to change in the process of constant comparative analysis.

3.5 Why Grounded Theory Approach

Denzin (1997, as cited in Patton, 2002, p. 487) describes grounded theory as the most influential paradigm in qualitative social science research. Fassinger (2005) maintains that this approach has been widely adopted by researchers particularly in the fields of health and nursing as well as education and psychology among others. Previous grounded theory studies in informal caregiving literature include, for example, accounts of how family caregivers perceive their interactions with health care providers (Caron, Griffith & Arcand, 2005) or nurse-family interactions (Jeon, 2004). Perry (2002) examined the process of “interpretive” caring for spouses with Alzheimer’s disease and Boland & Sims (1996) describe caregiving as a “solitary journey.” Lipkowitz (1992) conceptualised the caregiver’s conflict of providing good care while simultaneously providing for themselves. Willoughby and Keating (1991) explored the theme of “being in control” in the process of caring for a relative with Alzheimer’s disease.

Exploring injuries and physical pain in informal caregivers requires a sensitive technique that will capture the depth, diversity and complexity of their experience. Caregiving scenarios or situations differ considerably from family to family, as does the context in which injuries and physical pain may occur. Importantly, this is in an unexplored area, where previous knowledge is very limited. Therefore, grounded theory is well suited for the exploration of the informal caregiver's experience as it allows for "discovery" through the collection of detailed and rich data that varies from one scenario to another.

The secondary purpose of this study was to generate a conceptual framework that will be very practical and useful for the target population. The practicality of the grounded theory approach has been emphasized in the literature (Creswell 1998; Denscombe, 2003; Denzin and Lincoln, 1994). According to Denscombe (2003), grounded theorists argue that theories should be useful at a practical level and meaningful to those 'on the ground'. A "good" theory in the grounded theory perspective is one that will be practically useful to laymen in the course of daily events (Locke, 2001, as cited in Denscombe, 2003, p. 112). The grounded theory approach is thus well suited for the purpose of this study.

CHAPTER 4: LITERATURE REVIEW

In the past three decades, informal caregiving research has evolved from sporadic and anecdotal accounts of informal caregivers' experience into a substantial body of literature. Berg-Weber and Tebb (2003) maintain that the initial studies were somewhat skewed by small convenience samples of caregivers, who were usually recipients of formal services and frequently cared for older adults with dementia. Gradually, as caregiving research expanded, the outcomes of providing care for the family members received increasing attention.

Zarit et al. (1980) introduced the concept of *caregiving burden*, referring to the emotional and psychological distress experienced by family caregivers in the course of helping their elderly relatives. Much of the succeeding research focused on mental health effects of caregiving. Topics explored in caregiving outcome studies have included the following: caregiver depression (Chumbler, Pienta & Dwyer, 2004; Grant et al., 2000; Mitrani et al., 2006; Schwartz, 1999; Steffen et al., 1998; Stein et al., 1992); caregiving stress, its causes and mediating factors (Anderson et al., 1995; Chwalisz, 1992; Gonzales, 1996; Pearlin et al., 1990; Yates et al., 1999); and gender differences and related age and socio-economic factors (Campbell, 2000; Gallicchio et al., 2002; Navaie-Waliser et al., 2002; Pinquart & Sørensen, 2006). The effects of caregiving on the caregiver's physical health have also been examined (e.g. Baumgarten et al., 1992; Cattanach & Tebes, 1991; Fuller-Jonap & Haley, 1995; Grafström et al., 1992; Kiecolt-Glaser et al., 1991;

Lorensini & Bates, 1997; Scharlach & Runkle, 1994; Schultz et al., 1997; Schultz et al., 1995; Shaw et al., 1997; Teel & Press, 1999; Wells & Kending, 1997).

Berg-Weger and Tebb (2003, p.10) conducted a series of interviews with prominent scholars in the field of family caregiving. They concluded that

[w]hile research has revealed important information about the caregiving experience, inconsistencies in such areas as definitions, measurement, sampling, and intervention continue to plague some of the work in this area.

The scholars interviewed in their study agreed that caregiving is both a stressful and a rewarding experience with physical and mental health implications. In order to gain a more solid understanding of the caregiving experience and outcomes, future research must fill some of the gaps in the literature. Berg-Weger and Tebb (2003) suggest that this pertains particularly to the over sampling of dementia caregivers and under-representing those who care for frail older adults with chronic or terminal health conditions such as arthritis, diabetes, stroke or cancer. They recommend that caregiving research would benefit from studying change over time, diversity and the complexities and positive outcomes of caregiving rather than focusing solely on burden. However, these authors have not identified the gap in the literature with respect to physical pain and injury.

4.1 Informal Caregivers As the Backbone of Eldercare

The significant role of families in providing care for older adults with chronic health conditions is now widely acknowledged in the gerontological literature. Estimates of the extent to which eldercare is provided informally range from 72% (National Academy on Aging Society, 2000, as cited in Noelker, 2001) to 90% (Angus et al.;

1995). Chappell (1991) argues that informal networks account for 80 to 90% of all personal and instrumental care to the elderly.

In a Statistics Canada study on eldercare, it was reported that, in 1996, nearly 11% of the population 15 years of age and over provided informal care to one or more seniors with long-term health or physical limitations (Keating et al., 1999). About one in eight adult Canadians provided care to an individual with chronic health problems, usually an older parent. Approximately 22% of Canadians 65 years or over received care from another person because of a long-term illness or health problem. Those aged 85 and over received 89% of the assistance provided. The majority of informal caregivers were family members, primarily adult daughters, followed by spouses, who had been providing care for at least 2 years. Almost half of them (46% for females when compared to 70.5% males) were employed full time (Keating et al., 1999).

Family members tend to be involved in assistance with activities of daily living (e.g., bathing, dressing, toileting, feeding) and instrumental activities of daily living (e.g., transportation, meal preparation, housecleaning and maintenance, shopping, medication management, financial management). Keating et al. (1999) reported gender differences with respect to the type of help provided. Women were more likely to assist with meal preparation, housekeeping, personal care, shopping, banking, bill payment, checking on the care recipient and emotional support. On the contrary, higher proportions of men provided home maintenance and repair (Keating et al., 1999)

Informal care provision does not end when the care recipient is institutionalised. Research documents that family members do not cease their caregiving role and continue to be involved in care provision after the care recipient's admission to a care facility. For

example, Keating et al. (2000) found that family members provided about 30% of on-site services to residents in continuing care, mostly enhancing the care recipient's well-being, while staff spend most time providing housework. The involvement of family members in eldercare is thus a long-term commitment. Consequently, caregiving responsibilities and challenges can produce long-term effects on the caregiver's health and overall well-being that have not been fully explored in the caregiving literature.

4.2 Physical Pain and Injuries in Informal Caregivers

Investigations of caregivers' physical health have predominantly measured perceived health status, medication use, doctor visits and hospitalization, immune functioning, sleep disturbances or health behaviours in informal caregivers. Few studies have examined the occurrence of pain and injury in informal caregivers. Knowing the high rates of injury in formal, professional caregivers, our limited knowledge in this area is alarming.

In Brown and Mulley's (1997) U.K. study, 31 out of 46 informal caregivers interviewed had injured themselves while lifting and handling care recipients. Most sustained back injuries, and eight of the caregivers were temporarily unable to continue caring as a result of the injuries. Sixteen care recipients had been injured while being moved by caregivers. Less than half of the caregivers had received instruction in lifting and transferring the care recipients. In a qualitative study of informal caregivers by Sawatzky and Fowler-Kerry (2003), conducted in Saskatchewan, more than half of study participants sustained back injuries. Although it was unclear whether these injuries were directly precipitated by caregiving responsibilities, they were aggravated by caregiving.

Therefore, there is some evidence that injuries occur not only in formal caregivers but also in informal caregivers.

There are many commonalities in the caregiving experience for informal and formal caregivers, though some may argue that caring for a family member differs considerably from professional, paid, care provision. Yet both provide the same type of services in the same setting – the care recipient’s home. Noelker (2001) argues that both professional and family caregivers struggle to relieve the care recipient’s pain and discomfort and receive limited recognition for the heroic nature of their work. Similarly, both experience the negative effects of caregiving, including emotional distress, increased likelihood of depression, physical health problems and the challenges of balancing multiple demands (Noelker, 2001). Therefore, in situations in which professional caregivers are deemed prone to injury and physical pain, family caregivers are likely to be at the same, if not higher, risk.

4.3 Injuries in Formal Caregivers

While little is known about injuries and physical pain in informal caregivers, this area has been examined in formal caregivers. Injury rates for health care workers in BC are extremely high, especially for primary caregivers, such as nurses, orderlies, and care aids (NCE, 2005). In 2000, injury rates for social service workers and domestic workers were 7% to 30% higher than for other healthcare workers. Prevalence of injuries in these occupations was 65% to 100% higher than the average for all other workers in British Columbia. Providing assistance with activities of daily living within a person’s home was

identified as a health and safety challenge for the workers (OHSAH, 2005). A report by the Network of Centres of Excellence found that

[p]rimary caregivers account for 60% of serious injuries in BC. The main source of injuries is muscle strain accidents from pushing, pulling, lifting and carrying, which accounts for 54% of claims. Primary caregivers often have to work alone without any help in private residences that lack the proper equipment for lifting and transferring patients (e.g. from bed to wheel chair or wheel chair to toilet) (NCE, 2005, p.6).

The Occupational Health & Safety Agency for Healthcare in BC (2005) described the following occupational hazards for community health workers: physical or environmental conditions (poor lighting, broken stairs, small work spaces); exposure to biological and chemical hazards; exposure to environmental hazards; and potential violence or abuse from clients and others.

In a study of home care personnel, a number of physical and psychosocial factors were associated with complaints in the shoulder/neck area. The strongest physical factor was 'standing in forward-bent and twisted postures,' which is frequent in tasks such as lifting, dressing or transitioning from bed to chair. Stress was also identified as a significant psychosocial factor in explaining musculoskeletal conditions. Psychological stress was found to influence the load on shoulder muscles (Brulin et al., 1998). In another study by Brulin, Winkvist and Langendoen (2000), demanding physical and psychosocial working conditions emerged as the core variable contributing to the development and maintenance of neck, shoulder and low back complaints in female

home care workers. Thus, psychological stress associated with caregiver burden may increase the likelihood of caregiver injury.

4.4 Physical Health Outcomes of Informal Caregiving

Previous research on the influence of informal caregiving on caregivers' physical health has produced rather contradictory findings. Limited prevalence data is available. The extent to which caregivers' physical health is affected as a result of their caregiving role varies from one study to another. Schulz et al. (1995) reviewed the dementia caregiving literature. In one study, 70% of spousal caregivers had reported a doctor visit in the previous few weeks. In another, only 17% had seen a physician within the last month. As Pinquart and Sörensen (2003) note, this is due to both methodological and conceptual inconsistencies. Similarly, Berg-Weger and Tebb (2003) maintain that, while research has revealed important information about the caregiving experience, inconsistencies in definitions, measurement, sampling and intervention undermine knowledge in this area. Moreover, previous study designs have in most cases allowed only for capturing immediate, temporary physical health outcomes of informal caregiving. Longitudinal studies are needed for a comprehensive assessment of the long-term impact of informal caregiving on the caregiver's physical health.

Prior research has identified certain aspects of physical health that are affected by informal caregiving. For example, delayed wound healing was reported in caregivers (Huffman, 2000). In a study of male caregivers of a spouse with Alzheimer's disease, the caregivers experienced poorer physical health than demographically matched control

non-caregivers. This was only evident within limited domains such as the respiratory system and health behaviour (Fuller-Jonap & Haley, 1995). Informal caregivers seem to be more likely to perceive their physical health as fair or poor when compared to non-caregivers. Interestingly, self-assessed health was found to be a reliable predictor of actual and future health status or even mortality (Schultz, 1995).

In Connel and Gallant's (1999) review of literature on caregivers' health behavior, caregivers reported inadequate exercise and rest. Sleep disturbances, poor nutrition and changes in weight were experienced. Study participants were not attending to their physical health needs. For example, they tended to forget to take medications and did not have the time to rest or see a doctor when sick.

Connell & Gallant (1999) maintain that health behaviors may play a vital role in the maintenance and management of informal caregivers' health. They argue that the demands and challenges of care provision may limit caregivers' opportunities to engage in positive health behaviors, such as exercise and may trigger reliance on negative health behaviors, such as smoking or drinking. Other research documents inadequate self-care and detrimental health behaviors among informal caregivers. For example, lack of sleep or sleep disturbances are repeatedly reported across studies (Brummett et al., 2006; Kiecolt-Glaser et al., 1991; McCurry & Teri, 1995; Wilcox & King, 1999). A common complaint among caregivers is lack of time for leisure activities or social interaction (Carter et al., 1999). In conclusion, detrimental health behaviors, such as inadequate sleep or rest, poor nutrition, lack of exercise, not having enough time to rest when sick, forgetting to take medications and not having enough time for doctor appointments, could

explain, to a certain extent, adverse physical health outcomes of informal caregiving (Connel & Gallant, 1999).

Few caregiving studies have explored the negative effects of chronic stress. For example, in Schultz et al.'s (1995) review of literature, one study (Kiecolt-Glaser et al., 1991) found a significant decrease in the cellular immunity of informal caregivers, while another study (Irwin et al., 1991) reported no differences with respect to the activity of natural killer cells in caregivers and non-caregivers. O'Rourke and Tuokko (2000) suggest that the mechanism by which strain results in illness among caregivers is rather complex and specific stressors appear to impact different areas of the caregiver's health. Moreover, Pinquart and Sørensen (2003) conclude in their meta-analysis of caregiving outcomes that, frequently, caregivers do not complain of burden or other negative effects of caregiving due to their psychological resiliency, experience of positive aspects of caregiving or receiving stress-buffering support. Thus, the positive aspects of the caregiving experience and the caregiver's mental health need to be taken into account when exploring physical pain and injury.

4.5 Mental Health Outcomes of Informal Caregiving

The majority of caregiving studies have focused on the mental health outcomes of providing care to an older family member or friend. Previous research has centered on the notions of caregiver burden. Chronic stress, depressive symptoms, their causes and factors that may mediate the impact of chronic stress on the caregiver's well-being were studied.

Zarit and colleagues published their seminal work on *caregiver burden* in 1980. Consequently, numerous studies have explored this concept from a variety of perspectives (Allen et al., 1996; Anderson et al., 1995; Archibold et al., 1990; Chwalisz, 1992; Grafström & Winblad, 1995). Berg-Weger and Tebb (2003) maintain that caregiver burden is largely understood as a negative emotional response to the demands of caregiving. Bumagin and Hirn (2001) define caregiver burden as the deprivation of basic needs, disruption of relationships within the family, decreased social outlets and feeling of personal loss as perceived by caregivers. Difficulties in providing physical and fiscal care or lack of social stimulation among other factors potentially contribute to the stress of caregiving (Bumagin & Hirn, 2001). In Boland and Sims' (1996) qualitative study, burden or responsibility emerged as the strongest theme in informal caregivers' experience. Descriptions of burden included emotional, physical, financial and psychosocial components (Boland & Sims, 1996).

Previous research on depressive symptoms and emotional distress has documented poorer mental health in caregivers when compared to non-caregivers, even though findings vary among studies. In a longitudinal study by Cannuscio et al. (2002), caregiving was associated with increased risk of depressive or anxious symptoms. Grant et al. (2000) examined the psychological health of stroke survivor caregivers. Approximately one-third of the respondents experienced poor psychological health, with 37% of the caregivers presenting with depressive symptoms.

Mental health and physical health outcomes of informal caregiving cannot be viewed as strictly separate entities. Previous studies suggest that mental health and physical health outcomes of informal caregiving are inter-connected. Vitaliano et al.

(2004) note that much research has shown the association of chronic stress with sleep problems, risky health habits and illness progression in existing health conditions in general population. Distress and poor health habits elevate levels of stress hormones, which can lead to negative health outcomes such as hyperglycemia (elevated levels of blood sugar), hyperinsulinemia (elevated levels of blood insulin), higher blood pressure, and poorer immune functioning (Vitaliano et al., 2004).

On the contrary, Hubley et al. (2003) conclude in their survey that caregiving status alone does not appear to result in lower levels of quality of life or poorer mental health in older, married adults. Similarly, Pinquart and Sörensen (2003) reviewed literature on the differences between caregivers and non-caregivers in psychological and physical health. They maintain that even though substantial literature shows increased psychological distress in informal caregivers, these findings are inconsistent and contradictory. Caregivers' mental health may not be compromised, unless the caregiving situation is unusually stressful and there are no positive aspects to their caregiving experience (Pinquart & Sörensen, 2003).

Positive aspects of providing care to an elderly family member, such as reciprocal love and fulfillment, increased self-esteem, newly acquired skills or even a fresh network of friends through the caregiving role have been reported in the caregiving literature (Orzeck et al., 2001; Schofield et al., 1998). Willoughby and Keating (1991) have documented that, despite heavy responsibilities, the tasks of caregiving provided focus and meaning to the lives of caregivers. They found rewards in feelings of long-term reciprocity with the care recipient. Indeed, Perry (2002) argues that the caregiving process could be either positive, negative or both. Caregivers recognize their increased

skills and they express satisfaction with their ability to provide a good care (Perry, 2002). In Donelan et al. (2002) survey, 71% of informal caregivers reported an improved relationship with the care recipient. Many perceived their caregiving experiences as having a positive influence on their life.

The done study focused primarily on the negative experience, specifically on physical pain and injury in informal caregivers. However, positive aspects of caregiving were also examined, since rewards, benefits and the fulfillment of providing care to a family member play an important role in the experience and meaning of physical pain. Caregiving is a complex task and our understanding of the outcomes of informal care would be rather limited if we focused primarily on caregiver burden in isolation from the positive aspects of the caregiving relationship (McKee et al., 2003). Caregivers who feel less burdened and stressed may be more relaxed in their tasks and less likely to get injured. It is also possible that satisfaction with the caregiving role can alleviate or ameliorate emotional stress and help to mitigate negative perceptions of pain and suffering. Positive aspects of the caregiving experience can bring more positive meaning to pain.

4.6 Summary

The literature review shows that, although informal caregiving has received much attention in the past three decades, our understanding of family care provision as experienced by those involved in it is still somewhat limited. Inconsistent results across studies, different measures and rather loose definitions and use of terms and concepts jeopardize the practical use of research findings. It is apparent that investigations of this

phenomenon fail to reveal useful and reliable findings, unless they grasp the complex nature of the caregiving experience in its diverse contexts.

This is especially challenging when assessing caregiving outcomes in the areas of physical and mental health. Firstly, the experience of physical and mental health is very subjective, as is the meaning of health for different individuals. Therefore, the explanatory value of conclusions based on “objective” measures, such as hospital or doctor visits; medication use; number of chronic health conditions or days off sick is limited. Secondly, caregivers’ health is affected by interplay of factors. The current physical and mental health of caregivers is the result of a cumulative process throughout their life span. Even when comparing caregivers’ health to the health status of demographically matched non-caregivers, it is difficult to control for other factors that may explain the differences (such as personality traits, different life experience, past traumas and stressful life events, etc.). Moreover, some of the adverse effects of providing care on caregivers’ health may not emerge until later on in their lives, possibly years after ceasing their caregiving role. Hence, contextual analyses and longitudinal studies are needed in order to capture the multiple factors that effect caregivers’ health.

With respect to injuries and physical pain in informal caregivers, previous research provides little guidance for interventions and health promotion programs. Yet, studies suggest that caregiving can be hazardous and trigger injury and the resulting physical pain. Balancing challenges of work, caring for children and other family members and additional responsibilities creates role overload, which can result in fatigue, lack of concentration and impaired task performance. Yet, even in the face of their own health problems and limitations, informal caregivers continue to assist in physically,

mentally and emotionally draining activities. And given the commonalities in caregiving experience for professional and non-professional caregivers, the high injury rates witnessed in formal caregivers are likely to be replicated in family caregivers as well.

Accordingly, this study strives to fill a critical gap in the literature and provide the groundwork for future explorations of injury and pain in informal caregivers. A qualitative design utilizing the grounded theory approach and symbolic interactionism as a theoretical framework allows for a thorough analysis of the caregiver's experience. Diverse caregiving contexts in different families are thus taken into account, as are the meanings of injury and physical pain from the caregiver's perspective.

CHAPTER 5: METHODS

5.1 Qualitative Study Design

This research was designed as an exploratory qualitative study utilizing the grounded theory approach based on symbolic interactionism framework, as discussed in Chapter Two. This qualitative research design is appropriate for capturing the complex facets of the caregiving experience and, specifically, the experience of injuries and physical pain by informal caregivers. Recruitment strategies, characteristics of the sample and the methods employed in data collection, analysis and theory generation will be presented. Finally, several methodological limitations of this study will be acknowledged.

Gubrium and Sankar (1994) recommend qualitative research in situations where variables are unknown and where the focus is on the dynamics of a situation or the development of a relationship. The experience and meaning of injury and pain in the context of informal caregiving can therefore be explored more fully through unstructured and flexible interviewing techniques that are sensitive to contextual differences. Moreover, qualitative inquiry is very well suitable to investigations where the meaning or definition of the explored issues is unknown or contentious. Qualitative research has the ability to detect, represent, and explicate the meaning of something from the viewpoint of the actors involved. Gubrium and Sankar (1994) cite caregiving research as a domain in which qualitative research can yield valuable results. They argue that care provision may have diverse meanings from the viewpoint of policy-makers, professional caregivers and family caregivers. Researchers can gain insight into such different perspectives only

through the use of flexible and sensitive questioning instruments (Gubrium & Sankar, 1994).

Similarly, Mason (1997) notes that qualitative research employs methods of data generation that are flexible and sensitive to the social context in which data are collected, rather than rigidly standardized, structured and removed from real life. As previously noted, sensitivity to the caregiving context is critical to this study. The diverse context of care provision may significantly shape the experience and meaning of injury, pain and other physical discomforts for individual caregivers. Each caregiving situation is unique, as well as each caregiver and care recipient. There may be unresolved issues from the past relationship in family dynamics that could make caregiving tasks more stressful and challenging. Some caregivers may have strong personal resources, for example high levels of resiliency and optimism, whereas others may be prone to depression. In some families, financial circumstances may be adding more stress to the caregiving experience. In others, paid help may be contracted. Furthermore, some caregivers may be more resilient to pain and discomfort than others. Previous experience and knowledge of safe lifting could reduce the risk of injury. The caregiver's frailty, on the other hand, may increase the risk.

A study of the nature of the caregiving experience and the social context of the caregivers' experiences of injury and pain are well suited to Denzin and Lincoln's (1994) description of qualitative research:

The word qualitative implies an emphasis on processes and meanings that are not rigorously examined or measured (if measured at all), in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape inquiry (Denzin and Lincoln, 1994, p. 4).

Finally, Sandelowski (2004) maintains that qualitative health research is a “truly mindful methodology for improving the public health” (Sandelowski, 2004, p. 1382).

5.2 Recruitment Strategies

Prior to the recruitment of participants the Office of Research Ethics at the Simon Fraser University approved the study procedures. Respondents were informed about the study purpose and procedures. They expressed their decision to participate by signing a consent form. Caregivers’ responses collected for the purpose of this study were kept anonymous and confidential. Respondents’ contact information was stored separately from the questionnaires and the audio taped interviews. All of these study materials were kept in a secured location where they could be accessed only by the researcher herself.

Subjects for this study were recruited using multiple sources so as to maximize variability in the caregiving context. Initially, potential study participants were identified among the clients of the following agencies:

- Alzheimer’s Society of British Columbia (provincial organization focusing on the needs of individuals afflicted with Alzheimer’s disease and other dementias and their families);

- Caregivers Association of British Columbia (provincial charitable organization dedicated to supporting, informing and advocating for those who are caring for adult family members/friends);
- Caregiver Support Program (caregiver support groups in a number of community health centres within the Vancouver Coastal Health Authority);
- Century House, New Westminster, B.C. (senior centre offering a wide range of activities and services for older adults, including Alzheimer’s Support Group, Caregiver Support Group and Senior Peer Counseling);
- Stroke Recovery Association of British Columbia provincial organization assisting stroke survivors, their caregivers and family members).

Information about the study was distributed through the e-mail lists, newsletters and regular mail outs of these organizations. In addition, recruitment leaflets were posted in senior and community centres. These were also distributed at the Caregiver’s Forum, organized by the Caregivers’ Association of British Columbia in May 2006. A snowballing technique, which entails friends and acquaintances of those previously interviewed, was used to recruit additional study participants.

A total of twenty participants were interviewed. Initially, three caregivers were identified through a general practitioner. These caregivers participated in a pilot study for the purpose of testing the “Interview Guide” and are not included in the total number of twenty study participants. The majority of study participants (13) were drawn from attendees at the Caregiver’s Forum. Three caregivers identified themselves as clients of the Alzheimer’s Society of British Columbia and they brought additional two participants

who were their acquaintances. One caregiver responded to a recruitment leaflet in a community centre. Another decided to participate in the study after a brief recruitment speech in a caregiver support group organized by the Vancouver Coastal Health Authority.

5.3 Theoretical Sampling

This study utilized a “theoretical sampling” strategy, which is described by Denscombe (2003) as a process in which the sample emerges while theory is generated. The researcher simultaneously collects codes and analyzes the data. Data analysis guides further selection of the data to be collected and additional study sites. This strategy facilitates the researcher’s journey of discovery, wherein the developing theory is fully grounded in empirical data. Fassinger (2005) notes that the introduction of new data is directed by gaps, unanswered questions and underdeveloped ideas in the emerging theory.

The sampling process used in this research focused initially on dementia caregivers, as previous research suggested that providing care to a relative with Alzheimer’s disease or other types of dementia is particularly challenging and stressful. However, interviews with dementia caregivers contributed very little to the exploration of injury and pain. Three dementia caregivers interviewed in this study did not suffer from any injuries in the course of providing care and they did not complain of physical pain. Therefore, subsequent sampling sought caregivers to frail older adults that required physically challenging personal care. The three dementia caregivers with no experience of injury and pain were still included in the analysis and in the sample. Their responses

added to the emerging theory, as these caregivers, similarly to the rest of the sample, prioritized their care recipients' health and well-being, even when questioned about their own health concerns and needs.

Having interviewed five "stroke survivor" caregivers, new categories of care recipient conditions were purposively selected in additional sampling. More diversity in caregiving situations and challenges was thus introduced.

Eligibility criteria were based on a review of the literature. Eligible caregivers identified themselves as meeting all of the following criteria:

1. Informal caregiver: A non-professional, unpaid caregiver such as a family member or a friend who is in an informal relationship to the care recipient;
2. Primary caregiver: The person that bears the main responsibility for the care recipient, provides the most hours of care when compared to other potential caregivers;
3. Providing care for a minimum of six months: This allowed for an average adaptation period to life transitions as identified in literature and ensured that care provision was not temporary but has become embedded in the caregiver's life;
4. English language proficiency: The caregiver has sufficient understanding and communication skills in English so as to allow for meaningful conversation.

In order to fulfil the goals of this study in exploring the context of physical pain and injury, additional study participants were required to have:

5. Experienced physical pain or an injury: This experience was required to be directly connected to the individual's caregiving role, having occurred in the past six months at the latest.

5.4 Sample Characteristics

The socio-demographic background of study respondents [N=20] and some of the contextual factors in the caregiving situation are summarized in Table 5.1. and Table 5.2. retrospectively. Caregivers were predominantly female (n=13 or 65%). This gender distribution is common in caregiving studies. As discussed in chapter three, statistics show that informal caregivers are typically female (e.g. Keating et al., 1999), though there is a growing interest in the role of male caregivers and gender differences in providing care (Campbell, 1999; Gallicchio et al., 2002; Navaie-Waliser et al., 2002; Pinquart & Sørensen, 2006). Seven caregivers (35%) were husbands, with five (25%) caring for their wives with dementia and the remaining two (10%) helping a spouse with multiple sclerosis and post stroke. A spousal relationship to the care recipient was the most common (n=13 or 65%). The remaining caregivers were adult daughters caring for their elderly mothers (n=5 or 25%) and fathers (n=2 or 10%).

Table 5.1 Caregiver Socio-Demographic Characteristics (N=20)

Variable	Value	Frequency (n, %)
Age	Range	42-86
	Mean	67
Gender	Female	13 (65%)
	Male	7 (35%)
Marital Status	Never Married	3 (15%)
	Married	17 (85%)
Ethnic Background	Caucasian	19 (95%)
	Chinese	1 (5%)
Number of Children	Range	0-5
	Mean	2
Education	High School Diploma	4 (20%)
	Some College/University	11 (55%)
	University Degree	5 (25%)
Employment Status	Employed Full-Time	5 (25%)
	Employed Part-Time	3 (15%)
	Retired	11 (55%)
	Never Employed	1 (5%)
Annual Household Income	25,001 - 50,000 CAD	4 (20%)
	50,001 - 75,000 CAD	12 (60%)
	75,001 - 100,000 CAD	3 (15%)
	Over 100,000 CAD	1 (5%)

Table 5.2 Caregiving Context

Contextual Factor	Value	Frequency (n, %)
Caregiver-Care Recipient Relationship	Spouse	13 (65%)
	Daughter	7 (35%)
Care Recipient's Condition	Alzheimer's Disease	5 (25%)
	Stroke	5 (25%)
	Heart Disease	4 (20%)
	Hip Fracture	4 (20%)
	Severe Arthritis	1 (5%)
	Multiple Sclerosis	1 (5%)
Living Arrangement	Co-habitation	19 (95%)
	Separate Dwelling	1 (5%)
Care Recipient's Age	Range	74 - 94
	Mean	79
Care Recipient's Gender	Male	13 (65%)
	Female	7 (35%)
Duration of Care Provision	Range	13 months - 10 years
	Mean	4 years
Extent of Care Provided	Light	5 (25%)
	Intermediate	12 (60%)
	Complex	3 (15%)
Amount of Care Provision Per Week	Range	2 - 10 hrs
	Mean	16 hrs
Amount of Caregiver's Presence Required	Less than 5 hours/day	5 (25%)
	5 - 10 hours/day	9 (45%)
	Constantly	6 (30%)

The purpose of this study was to explore injury and physical pain. Therefore, older caregivers providing for frail relatives were sought. It was assumed that those providing more “hands-on” personal care (including lifting and transferring) would be at a higher risk for injury or pain from muscle strains. Moreover, spousal caregivers are often facing their own deteriorating health and declining functional status, which leaves them especially vulnerable.

Three caregivers (15%) were single (never married) and the rest were married. The mean caregiver age was 67, ranging from 42 to 86. Care recipients were between 74 and 94, with the mean at 79. More than half of the sample (11 or 55%) was retired, five caregivers (25%) worked full-time, three (15%) part-time and one (5%) was never employed. One caregiver (5%) identified herself as Chinese, the remaining Caucasian.

In the process of theoretical sampling, a conscious attempt was made to include caregivers with less education and lower income. Caregivers with lower education and income may be less informed about formal supportive services and interventions. Additionally, they could lack financial resources to purchase respite or home support services. Reaching low income and less educated caregivers proved to be very challenging, though multiple recruitment strategies were employed. The resulting sample is still fairly well-educated with over half (11 or 55%) of the caregivers attaining some college or university education, five (25%) holding a university degree and four (20%) completing high school.

The majority of the caregivers provided care to frail older adults (15 or 75%), although five caregivers (25%) interviewed at the initial phase of the study were helping

a family member with Alzheimer's disease¹. The main causes of care recipients' care needs in the sample of fifteen frail older adults were the following: heart disease (n=4 or 20%), stroke (n=5 or 25%), hip fracture (n=4 or 20%), severe arthritis (n=1 or 5%) and multiple sclerosis (n=1 or 5%).

Previous research has identified co-habitation as one of the contextual factors that further the adverse impact of caregiving on the caregiver's health (e.g. McCurry & Teri, 1995). Caregivers who live in the same household as the care recipient are in most cases the primary caregivers and they tend to provide more hours of care per week. They are also more likely to be assisting the care recipient with personal care, as compared to those living in separate dwellings (Keating et al., 1999). Caregivers in this study have been providing care an average of 16 hours per week from thirteen months up to ten years (mean=4 years). Most of them defined the level of care provided as intermediate (n=12 or 60%).

¹ This was an estimated diagnosis by a physician.

5.5 Data Collection

Data were collected through face-to-face in-depth interviews with informal caregivers in their home. The care recipients were not present in order to provide for a more open and relaxed conversation, especially when negative issues and caregiving challenges were discussed. The interviews took on average 90 minutes and were tape-recorded. At the same time, notes were taken and included the researcher's observations with respect to the physical environment where care was provided and the caregiver-care recipient relationship or family dynamic. Each participant was involved in two interviews. In the initial interview, caregivers responded to the questions and probes in the "Interview Guide" and shared their experiences with providing care, injury and physical pain. The second interview served for "member-checking". This is a method used in validating the researcher's interpretation of the caregiver's experience. Caregivers' feedback and insight with respect to the researcher's understanding of their experience was included in further data analysis. The second interview also provided opportunities to explore themes and issues that emerged in interviews with other caregivers.

An interview guide (see Appendix) was used to ensure consistent data collection. This instrument was developed and tested in pilot interviews with three caregivers. First, one caregiver was prompted to share her experience with injury and pain in general probes: "Tell me about your experience as a caregiver." "What is your experience with injury in the course of helping your spouse/parent/etc.?" "What is your experience with physical pain while providing care?" The rich data collected in this interview guided the

selection of predominantly open-ended questions in the Interview Guide. This tool was then administered in interviews with two informal caregivers and subsequently modified and re-worded based on the feedback from these interviewees. The Interview Guide served as a guideline in order to guarantee that all of the important questions were asked. However, it was defined as a guideline and used as such. Each interview was approached with an open mind and study participants were encouraged to go beyond the boundaries of predefined research questions in sharing their experience.

According to Denscombe (2003), grounded theory studies embark on a “route of discovery”. Research questions are continuously modified as new, unexpected themes and concepts emerge through ongoing data analysis. Strauss and Corbin (1990) maintain that the initial questions or area of observation must be considered provisional in the grounded theory approach, as they have not yet supported theoretical relevance to the evolving theory. The initial questions and research issues that were outlined prior to data collection were modified in the process of interviewing and data analysis. The original interview guide was slightly altered in the process. A few sub-questions were discarded, as they did not yield any significant addition to the research area, whereas other interesting themes were explored with additional questions.

5.6 Data Analysis

A “constant comparative method” of data analysis as described in Creswell (1994), Denscombe (2003), Fassiger (2005) and Strauss and Corbin (1994) was used in this study. This is a process of comparing the information from data collection to emerging categories. According to Charmaz (2000, as cited in Fassiger, 2005), this

process includes comparing data from different individuals, data from individuals at different points in their narratives, comparing incidents with other incidents and comparing categories with other categories.

Data analysis was thus an ongoing process starting from the very initial data collection. After each individual interview, tape-recorded material was transcribed verbatim and coded using manual coding techniques. Strauss and Corbin's (1990) "coding paradigm" was followed. Kelle (2005, p.21) maintains that the

[c]oding paradigm is especially helpful to beginning analysts. It consists of four items, namely "conditions", "interaction among the actors", "strategies and tactics", "consequences", which can be used explicitly or implicitly to structure the data and to clarify relations between codes.

These categories were especially helpful in the first analytical phase, where individual caregiver responses were roughly structured. For example, "conditions" included any responses relating to the type of injury or physical pain or the caregiving situation, such as cohabitation, relationship to the care recipient, etc. "Interaction among the actors" encompassed notes of family involvement in care, conflict with care recipient or care recipients' expressing concerns about the caregivers' health. "Strategies and tactics" described ways of care provision, means of coping with challenges, etc. In "consequences" negative and positive effects of caregiving, injury and pain were included. A "map" of the individual's caregiving experience was then developed, based on the structured data. This map served as a simple diagram with a number of categories. Connections, causal and intervening factors were drawn between the categories. Individual maps were subsequently compared and combined in the process of overall analysis that included data from all interviews.

Complete raw data from all interviews (the full document of interviews transcribed verbatim) was then thoroughly analysed and restructured. Computer word searches assisted in determining how frequently certain terms reappeared among interviews and the strongest or most common codes were identified. Comparing individual maps and structured data among study participants, overarching categories were developed. Gradually, a "master map" was created, summarizing the experience of injury and pain in all study participants. This was a fairly detailed diagram, including information from each interviewee. Finally, "conditional matrix" of the multidimensional and contextual conditions influencing injury and physical pain in informal caregivers was generated.

Memos collected during the interviews were incorporated into the analytical process. Fassinger (2005, p.164) argues that researcher reflexivity needs to be made apparent in the grounded theory approach:

Memo writing on the part of the researcher occurs continually throughout the research process and provides a record of conceptual, procedural, and analytic questions and decisions. Memo writing captures the evolving ideas, assumptions, hunches, uncertainties, insights, feelings, and choices the researcher makes as study is implemented and as a theory is developed, providing means for making transparent the interpretive, constructive processes of the researcher.

5.7 Ensuring Rigour

The study limitations are discussed in Chapter Eight, as well as the extent to which the study findings can be generalized. Overall, sampling, data collection, data analysis and theory generation in this study followed a systematic and thorough method. A variety of tools have been developed to achieve scientific rigour in qualitative research. Seale and Silverman (1997) suggest the following techniques of ensuring reliability and

validity in qualitative research: supporting generalizations by counts of events, ensuring representativeness of cases, consideration of deviant cases, using computer programs for systematic analysis and recording data objectively and comprehensibly.

An interview guide was developed and tested in a initial pilot study. This guide ensured that all of the interviewees were asked the same questions and data collection was thus consistent and systematic from one interview to another. The interview guide was slightly modified during the interview process, responding to newly emerging themes. However, newly added questions were included in the second interview for those who have not responded to them in the initial interview.

Data collection followed the same procedures in each interview. All of the interviews were conducted in the participant's home without the care recipient present and by the same researcher. All interviews were fully audio-taped and transcribed verbatim. The analytical process was structured and consistent for each interview. Some computer program analysis was used, adding a more objective and systematic technique of analysis.

Finally, in describing the results in Chapter Seven, frequency (how many cases) of each event experienced by study participants is provided. The sample is thoroughly described, as well as all of the study procedures. This way, the reader can determine the extent to which he or she can generalize study findings to his or her own experience.

CHAPTER 6: RESULTS

In the process of data collection and analysis, interesting new theme emerged with respect to the meaning of physical pain and injury to the caregiver. Surprisingly, caregivers were repeatedly reporting being more concerned about the pain, discomfort or health problems experienced by the care recipients. It seemed that the caregivers' health was secondary and less important in the process of providing care to their loved ones and in ensuring their well-being. These intriguing trends were further explored in the subsequent data collection and yielded significant new findings. These findings and the substantive theory that was generated are the main contribution of this study.

This chapter was organized to reflect the initial research sub-areas that were described in Chapter Two. This structure does not reflect the analytical process, in which new themes and categories were discovered. However, such presentation of caregivers' responses to the initial questions allows for the reader's orientation in this text. The findings in this chapter are plainly descriptive. Contextual factors are fully explained in Chapter Seven.

The overarching research question is “What is the context in which physical pain and injuries are experienced in informal caregivers for older adults?” Six sub-areas have been explored: the caregiving situation and injury and pain in informal caregivers; the consequences of physical pain and injuries in informal caregivers; problematic aspects of the caregiving experience; positive aspects of caregiving and their role in explaining physical pain and injury; caregiver coping strategies; personal, social, economic and

community resources utilized by informal caregivers in dealing with physical discomforts and preventing injuries.

6.1 Experience of Injuries and Physical Pain in Informal Caregivers

Injuries sustained by study respondents included muscle strains (n=3); falls (n=3); ankle sprains (n=2); twisted knee (n=1); dislocated shoulder (n=1); broken wrist (n=1); burns (n=1); and bruises (n=1). Physical pain experienced by the caregivers ranged from mild (n=9) and moderate (n=7) to severe (n=3) and it affects mostly shoulders and neck (n=6). Other areas with physical discomfort included lower (n=3) and upper back (n=2); ankles (n=2); knees (n=2); hips (n=2); elbow (n=1), arm and hands (n=1), calf and hamstring muscles (n=1). Two caregivers complained of frequent headaches. These findings are similar to those reported in previous studies with respect to professional caregivers. According to Brulin et al. (2000), neck, shoulder and lower back complaints are common among home care workers. In Brown and Mulley's (1997) U.K. study, seventeen out of the forty-one informal caregivers suffered from back pain, seven from muscular aches and pains, two from hernia, and one has twisted her knee.

The types of injuries and physical pain experienced by the study participants, as well as the injury or pain triggers and consequences from the caregiver's point of view are summarized in Tables 6.1 to 6.3. Separate tables have been created for the purpose of comparison between male and female spousal caregivers and adult daughter caregivers. Female spousal caregivers (n=6; mean age 76) were found to be somewhat younger than male spousal caregivers (n=7; mean age 78) and the adult daughter subgroup was considerably younger (n=7; mean age 49). Moreover, men were predominantly caring for

their wives with Alzheimer's disease and therefore were less likely to provide physically demanding "hands-on" care. The experience of injury and physical pain differed among these subgroups.

Male Spousal Caregivers

The types of injuries, body areas affected by physical pain, injury and pain triggers and consequences in male spousal caregivers are summarized in Table 6.1. Male spousal caregivers did not suffer from any serious injuries. None of the dementia caregivers have sustained an injury, although one caregiver complained of frequent headaches, related to 'caregiving stress'.

I've been getting these headaches lately. I think it's the worrying and thinking, you know; the stress that's kind of typical caregiving stress for those of us who have lost our loved ones. I mean, Joan² is still around but it feels like I've lost her - we've lost our communication. (Frank, husband, 86)

Another dementia caregiver reported a pre-existing condition, an arthritic knee, which has caused him difficulties in performing housekeeping tasks and contributed to his worrying about his wife's future need for personal care. The only injury reported in male study participants was an ankle sprain, caused by a slip on a wet bathroom floor while helping the care recipient get out of the shower. Finally, a husband who has been assisting his wife with multiple sclerosis complained of moderate lower back pain that may have been caused by continuous lifting and transferring. Consequently, the two reported cases of physical discomfort negatively affected mood, sleep and energy level in male caregivers.

² Pseudonyms are used in verbatim responses in order to ascertain the study participants' anonymity and confidentiality.

Table 6.1 Injuries and Physical Pain in Male Spousal Caregivers

Age	Care Recipient Condition	Type of Injury	Physical Pain	Affected Area	Injury/Pain Trigger	Consequences
86	Alzheimer's Disease	None	Mild Pre-existing mild pain	Headaches Knee (Pre-existing condition)	Chronic stress; worrying about wife; grief at lost communication	Irritability, lack of concentration, sleep disturbances, fatigue
82	Alzheimer's Disease	None	None	-	-	-
80	Alzheimer's Disease	None	Mild	Knee – arthritis	-	Difficulties in performing house-keeping tasks, inability to provide personal care if needed in future
78	Alzheimer's Disease	None	None	-	-	-
76	Alzheimer's Disease	None	None	-	-	-
74	Stroke	Muscle strain	Moderate	Quad and calf muscles on right leg	Slip on wet surface (bathroom floor)	Hospital visit, pain for 3 weeks, inability to provide care for 3 weeks
72	Multiple Sclerosis	None	Moderate	Lower back	Lifting and transferring on an everyday basis; decreasing strength and deteriorating health	Moderate discomfort in performing caregiving tasks; disturbed sleep, contributed to the caregiver's decision to give up golf; use of pain killers

Female Spousal Caregivers

Injuries were more common in female spousal caregivers and their consequences were more severe as compared to male spousal caregivers and adult daughters. The findings for this subgroup are summarized in Table 6.2. In total, there were six female spousal caregivers and four of them sustained an injury while providing care. These injuries include muscle and back strains, dislocated shoulder and a fall resulting in bruises and a broken wrist. All of the study respondents in this subgroup complained of some kind of physical pain, most commonly shoulder, neck and back pain. One caregiver has strained her hamstring and calf muscles and twisted her knee due to a trip on a stair. Other areas affected by physical pain included a bruised hip and a broken wrist. One caregiver in this subgroup complained of headaches. All of the injured female spousal caregivers visited the emergency department for treatment of their injuries. Care provision was affected by continuing physical discomfort or chronic pain in the caregiver. In two events, the care recipient was lightly bruised as well. Also, sleep was negatively affected and two caregivers relied on painkillers to relieve their pain.

Table 6.2 Injuries and Physical Pain in Female Spousal Caregivers

Age	Care Recipient Condition	Type of Injury	Physical Pain	Affected Area	Injury/Pain Trigger	Consequences
84	Heart Disease	Muscle strain Muscle strain Twisted joint	Moderate Mild Moderate	Hamstring Calf Knee	Trip on a stair while assisting care recipient on way to the bedroom	Hospital visit; continuing knee pain; use of pain killers; care recipient bruised
79	Stroke	Back strain	Severe	Upper back, shoulders, neck	Quick, sudden movement while making bed; chronic stress and caregiver deteriorating health	Hospital visit; continuing physical discomfort and pain; family (daughter) had to take over provision of personal care
78	Heart disease	Fall resulting in bruises and broken wrist	Mild	Bruised hip Broken wrist	Missed step (turned back to answer husband's call while on the way out of the house)	Hospital visit; immobilized wrist for 2 months; family had to take over caregiving responsibilities for 3 months; weakened wrist affected care provision
74	Heart disease	Cannot recall	Moderate	Headaches Shoulders and neck	Cannot recall	Restless sleep; fatigue; worrying about the future
73	Stroke	Dislocated Shoulder	Severe	Right shoulder	Attempt to prevent care recipient fall	Hospital visit; severe pain for 2 weeks, continuing sensitivity in right shoulder; respite care needed for 2 months; professional caregiver hired for 12hrs a week (financial strain)
69	Stroke	None	Mild Moderate	Shoulders, neck Lower back	Multiple responsibilities (having to maintain the house and yard without help); inadequate rest;	Physical discomfort; use of pain killers; restless sleep; fatigue; conflict with adult children over care responsibilities

Adult Daughter Caregivers

Four out of the total of seven adult daughter caregivers reported some kind of an injury in the course of providing care. Their injuries included muscle strain, sprained ankle and light burns. Two caregivers fell with one fall resulting in a knee injury and one in minor bruises. All of the adult daughter caregivers complained of physical pain, such as headaches, joint, back, neck and shoulder pain. One caregiver suffered from mild pain due to light burns on hands and forearms and a bruised hip and arm.

It happened twice to me already in just a few months! I'm always in so much hurry to get mum settled and then rush back to work or home to my kids. ... First I got burnt. ... I had a frying pan on, one of those heavy old-fashioned ones in mum's kitchen. I hear this noise, as if she fell off her bed, so I left everything and run to help her. She was fine, nothing happened. But then I run back to the kitchen, oil's burning on the pan and as I'm trying to get it off the fire quick, I grab it with bare hands! ... About a month later, the same thing again! I'm helping mum upstairs, someone rings the bell and as I'm running to answer the door for her, I slip and fall on the stairs (Liz, daughter, 49)!

Another reported mild pain in the right arm that caused her minor physical discomfort.

The consequences of these injuries and pain in adult daughter caregivers were predominantly temporary and minor. However, one caregiver suffered a serious knee injury that had a lasting adverse effect on her overall well-being.

I'm in constant pain. Some days it's worse, some days I almost forget about it—until I decide to kneel down or make a sudden move or something. Everything is changed since! I find driving very difficult, so I started taking a bus instead. ... Helping my mum? ... If it goes like this, someone will have to take over. I mean, she's needing more and more help and I can hardly lift her or have her lean on me with this bad knee (Dita, daughter, 52)!

Table 6.3 Injuries and Physical Pain in Adult Daughter Caregivers

Age	Care Recipient Condition	Type of Injury	Physical Pain	Affected Area	Injury/Pain Trigger	Consequences
56	Stroke	None	Mild	Elbow Lower back	Heavy lifting; care recipient's unwillingness to cooperate	No major consequences recalled by caregiver; minor physical discomfort while assisting with personal care
53	Hip fracture	Muscle strain	Moderate	Shoulder Upper back	Cannot recall exactly; physically challenging care tasks (transfers, lifting)	Physical discomfort; 3 days work absence;
52	Heart disease	Fall	Severe	Knee	Slip and fall while assisting mother with bath (against her will)	Severe knee pain lasting 2 months; continuous physical discomfort affecting all aspects of caregiver's life (limited sport activities, pain while providing care)
49	Hip fracture	Burns Bruises from fall	Moderate	Hands and forearms Hip, arm	Lack of concentration and multitasking, missed step while rushing to answer the door	Doctor visit; 1 week absence from work; physical discomfort for 2 weeks
47	Hip fracture	None	Mild	Neck Right arm	Trying to speed care tasks in face of multiple responsibilities and limited time	Minor physical discomfort
44	Severe arthritis	None	Mild	Headaches	Chronic stress; limited time to rest	Lack of energy; frequent arguments with husband
42	Hip fracture	Sprain	Mild	Ankle	Trip on carpet while providing care in care recipient's home	Minor physical discomfort

6.2 Injury and Pain Triggers

Caregivers reported the following injury and physical pain triggers: slips and trips, including missing a step (n=5); physically challenging care tasks, such as lifting transferring or helping with personal care (n=3); chronic stress (n=3); multiple responsibilities resulting in lack of concentration and speeding caregiving tasks (n=3); and inadequate rest (n=2). One caregiver strained her back while making the care recipient's bed. Muscle strains and joint injuries resulted from slips or trips and falls, whereas back and arm pain were attributed to heavy lifting. Chronic stress was believed to have caused headaches, shoulder and neck pain. Female spousal caregivers complained of the physical demands of care provision while facing their own functional decline and health problems. Adult daughters frequently admitted to having limited time for care provision. In the face of their multiple responsibilities, adult daughters were trying to get things done as fast as possible or even against the care recipient's will.

Well, it's too much to handle. ... I have a demanding job too, you know, one that keeps you thinking about what you should have done and what you'll need to do next day. ... And then shopping for mum and shopping for my family, cooking – and you want your share of down time too, read a book, watch a movie. That's why I rush everything, I'm always on a run and you see what happens (Liz, daughter, 52)!

Three out of the seven adult daughter caregivers noted that their elderly parents repeatedly refused having a bath, which caused conflict and the care recipient's unwillingness to cooperate. One caregiver suffered a serious knee injury while assisting her mother with bathing against the mother's will.

If it was up to her, she just wouldn't bathe at all! We had a helper from home support and mum kept complaining that she comes too late in the day or too early and that it's not convenient, and who knows what. ... When I took over, I tried being really flexible. I mean, who wants to have a shower at 2:30 pm? But it's not that! She just doesn't care anymore! It's a struggle every time – first we argue for half an hour, then I get angry and force her – like a child – and then she's mad at me, sitting like a doll and having me do all the work. That makes it really hard (Caroline, daughter, 47)!

Further discussion of contextual elements in the experience of injury and pain follows in Chapter Seven. The substantive theory of 'accentuating care recipients' well-being' versus 'attenuating caregivers' well-being explains some of the processes that may trigger injury or pain in informal caregivers.

6.3 Consequences of Injury and Pain

As previously mentioned, the consequences of injury and pain differed for the male spousal, female spousal and adult daughter caregiver subgroups. Unfortunately, the scope of this study only allowed for documenting the immediate outcomes of injury and physical pain. Long-term effects could not be observed. Moreover, caregivers recalled these consequences subjectively and retrospectively, though in many cases the caregiver's experience of physical pain was current and continuing.

The effect of injury and pain on the caregiver's overall well-being was most pronounced in female spousal caregivers. Injuries led to hospital visits and short term inability to provide care. In two cases, extra help was needed in the long-term following the injury. In one scenario, an adult daughter took over the more physically demanding care tasks, while the other caregiver hired part-time help. This caused an additional financial strain for the caregiver. Other outcomes of injury and physical pain in female

spousal caregivers included use of pain killers, sleep disturbances and fatigue, difficulties in providing care and conflict with adult children over care responsibilities.

Three male spousal caregivers experienced injury or physical pain that they believed was directly associated to their caregiving responsibilities. One of them had to be treated at the emergency department and was unable to provide care for three weeks. Another male spousal caregiver complained of moderate physical discomfort in performing caregiving tasks; sleep disturbances, use of pain killers and giving up his hobby (golf) due to lower back pain.

It's hard to tell, what is natural as we age and what harm is done by the physical part of helping my wife. I'm fairly strong and healthy but who knows – all those years of lifting and helping her to bed and then to her chair. This lower back pain is really part of my life now. But I never had any back problems before, so that must be it. She's a bit overweight too. ... Not easy to lift or help when you're seventy-two (Steve, husband, 72)!

In adult daughters, injury and pain had typically minor consequences in the sense of mild physical discomfort for a limited period of time post injury. Three out of the seven adult daughter caregivers reported a short absence from work (from three to seven days) due to their injury. One adult daughter complained of frequent headaches, resulting in a lack of energy and a deteriorating relationship with her husband. One daughter suffered from chronic knee pain that had an adverse impact on many aspects of her life and made some care provision tasks painful and uncomfortable.

6.4 Caregiving Challenges

Study respondents were asked about the challenging aspects of care provision. Again, differences were observed in caregivers based on their age and relationship to the

care recipient. Understandably, the experience of male spousal caregivers providing for their wives with Alzheimer's disease was notably different from the rest of the study participants. They expressed grief and feelings of loss, and loneliness and isolation when faced with their wives' gradual cognitive decline. Fear of the future, anger, fatigue and irritability were reported. Loss of meaningful communication with their loved ones, care recipients' personality changes, challenging behaviour and not being recognised by the care recipient were the major challenges and concerns for these caregivers.

Female spousal caregivers, on the other hand, found providing care physically challenging in the face of their own functional decline. They admitted to fear of the future and being worried about their ability to continue providing care. They also reported feeling trapped and not having enough time to relax and participate in activities outside their home. As a result, they felt that their social networks were shrinking:

It's almost like you become a different person, different personality. We used to love our social life.... We had so many friends! I started feeling bad about going out and then coming back and seeing John here on his own, bored and lonely. He never complained and he wanted me to enjoy myself – but we've always done these things together and it breaks my heart to leave him. Of course, we're at that age when your friends start disappearing one by one, what can you do. But some we just lost touch with (Cathy, wife, 79).

Lack of understanding and appreciation from family members, especially adult children, was another challenge for female spousal caregivers. Three out of the six wives complained that they were left alone with care provision and their children contributed very rarely:

They tell me, “You worry too much, mum! Dad’s fine on his own for a bit, don’t feel like you always have to be there. Get a break and you’ll be all fresh when you come back.” Well, they’re not there to see the changes! Jon’s really gone down and who’ll be there to call help if his heart gives out? I’ve always been the strong one, happy and optimistic, I was giving everyone courage and cheering them up. They are stubborn to see me like that – I can’t get them to see, how serious things have become (Sue, wife, 74).

Adult daughters reported multiple responsibilities (work, family, caregiving) as one of the greatest challenges of providing care. Three out of the total seven complained of the care recipient’s “resentment to care,” especially with respect to personal hygiene. Similar to wives caring for their elderly husbands, adult daughters felt that they were left alone in care provision and other siblings or family members contributed only occasionally, and to a limited extent. Also, family conflict and disagreement in decision making about the care provision, were reported as a challenging experience for female spousal caregivers. One daughter, who was the only caregiver not living with the care-recipient, noted that she found it difficult to assist her mother with activities of daily living in the mother’s confined and cluttered apartment.

6.5 Caregiver Coping Strategies

When dealing with caregiving challenges and the consequences of a potential injury or pain, caregivers employed a variety of both positive and negative strategies. Interestingly, religion and faith or spirituality was commonly reported as a source of strength and perseverance in face of the caregiving challenges. Caregivers were asked, whether they considered themselves to be not religious at all, somewhat religious, moderately religious or very religious. Additionally, they responded to the same question but this time relating to their spirituality. Five caregivers (25%) considered themselves to

be not religious at all and three (15%) were not spiritual at all. Six caregivers (30%) said that faith and religion provided them with continuous help in their caregiving role, and nine (45%) relied on their spirituality. Prayers, meditation and attending religious services were seen as important stress relievers and vital components of the caregiving role.

I pray everyday and ask God to give me the strength to keep on going. Some days, the bad days, when Bill is suffering, just sitting in the chair-- he can't enjoy walks anymore-- I am so destroyed to see him suffer! I have to leave the room and say a little prayer, helps me calm down and return all smiling and encouraging again (Sara, wife, 69).

No, I don't go to Church. I was never raised that way... I could not be a part of an organized religion, doesn't fit my personality and my own faith. But I have my little sanctuary here in the sun-room, a place to close my eyes and immerse myself in peace and quiet. That helps me tremendously; I'd go nuts by now without this (Caroline, daughter, 47).

Other positive coping strategies included socializing (meeting with friends, talking with friends or family on the phone, e-mailing); creating a 'sanctuary' or respite (regular time or space on his or her own); music; reading; creativity (knitting, quilting, art, gardening); reaching out for help (formal and informal); exercise (swimming, walking, jogging, golf); volunteering; and spending quality time with the care recipient.

Well, my friends are keeping me strong. They are wonderful! I can hardly find the time to call them and I keep forgetting everybody's birthdays but they're not giving up on me! Oh, they are so understanding! Phoning to say Hi and give me a bit of encouragement... I have a friend who drops by here and there, always with a lovely pie. I used to love to bake and now I don't have the time, so it's such a treat for me and for Jon (Sue, wife, 74).

My daughter and grandchildren are amazing. The kids come by for a visit and they would entertain 'grandpa', cheer him up and bring smiles on both of our faces. That lights the whole day, you know - we get a good laugh, which doesn't happen too much anymore when we're on our own (Judy, wife, 78).

Caregivers also admitted to using negative coping strategies in response to caregiving challenges. The majority of the caregivers (n=12 or 60%) confessed that they have been neglecting their own health to some extent. Two caregivers (10%) reported overeating and one (5%) an increased consumption of alcoholic beverages as a coping strategy. On the emotional level, four caregivers (20%) reacted with resentment and anger. Withdrawal from hobbies and activities was commonly reported (n=7 or 35%) as was isolating oneself from family and friends (n=5 or 25%).

I have bowls with candy and chocolate bars in each room now. I must be eating more chocolate than I have ever had in my life! But I always used to do this as a 'pain killer', emotional 'pain killer'. It works short term but my dentist won't agree. Good thing I don't seem to put on extra weight. (Ann, daughter, 56)

Sometimes I am so mad at Bill... I know it's not his fault but he can be difficult and picky and critical! I lose control and start yelling and accusing him. Few months ago I threatened him that I'll just leave him one day if he complains. That's pretty bad, isn't it? I mean, I know that I should be understanding and I shouldn't take things personally but Bill's not an easy patient, really (Sara, wife, 69).

6.6 Positive Aspects of the Caregiving Experience

Caregiving was seen as a positive experience as well as a challenging and demanding role. However, study respondents were predominantly overwhelmed with the challenges and difficulties in providing care. This is understandable, given the focus of this study on caregivers who have sustained an injury or suffered from physical pain as a result of their caregiving tasks.

Good things? ... Well, you know I'm too tired to think of that. ... I mean I'm happy that I can help mum and it's important for me to know that she has everything she needs. And I'd rather burn out than have her go to a home, she made it clear that leaving her house would kill her. She spent 35 years there! So yeah, I'm happy that I can keep her there (Liz, 49, daughter).

Nine (45%) caregivers expressed their satisfaction with knowing that the care recipient was well cared for and that he or she was able to stay at home, due to their involvement in care provision. Seven (35%) caregivers felt good about themselves for helping their relatives, notwithstanding the difficulties. Two (10%) caregivers reported feedback and appreciation from family and friends as a positive aspect of their caregiving role.

My daughter calls me every night, just for five minutes or so. ...She never forgets to tell me, what a wonderful example our love to each other is for her family! They'd love us to move to Edmonton and live with them. ... I think they feel guilty that they're not around to help. Isn't that funny, though, it makes me proud to know that my children have so much respect for me, also because I take care of George (Betty, wife, 84)!

Finally, one caregiver reported an improved relationship with the care recipient as a result of her care provision. Interestingly, two caregivers (one female spouse and one adult daughter) said that they could not think of anything positive in their caregiving experience.

6.7 Caregiver Resources

Caregivers utilized a wide range of formal and informal resources in dealing with their caregiving responsibilities. On the *personal* level, study respondents most commonly reported optimism, resiliency, knowledge and skills acquired in the life course. One caregiver was a retired licensed practical nurse. She noted that her career and

health-related knowledge helped her significantly in providing care to her frail elderly husband:

When I talk to other people in our (stroke recovery caregiver support) group, they say that the first few months were really hard on them. They had to learn how to take care of a sick person and gain more confidence – I’ve had that all my life, helping people that were in much worse condition than Bill. I knew all about making him comfortable and taking a good care of him. I didn’t need to gain confidence. But it was really hard too, ... I felt for him, he hates having to rely on others (Sara, wife, 69).

Social resources were a significant source of caregiver support. Phoning friends or family members was a common strategy in “keeping sane” and dealing with caregiving challenges and with the consequences of potential injuries and physical pain. The majority of the study respondents reported only an occasional help from other family members. In one case, adult children took over care for a limited period of time after the caregiver sustained an injury. In one family, injury resulted in adult daughters’ involvement in providing care for an extended period of time (three months). Yet another adult daughter took over the physically challenging aspects of care (e.g. bathing) after her mother’s injury. Primarily however, families and friends were sought out for emotional support, advice and encouragement rather than as a source of instrumental help in caregiving responsibilities. Some caregivers (n=4 or 20%) mentioned that their neighbours were a source of occasional instrumental support. Neighbours' help included walking the caregiver's dog, cutting the lawn and occasional grocery shopping. The church community was cited as a source of emotional, psychological and spiritual support in six caregivers (30%). Four caregivers (20%) noted that they found new social support networks through formal caregiver support groups.

Economic resources were seen as very important in care provision. Four out of the five dementia caregivers had sufficient financial resources to hire a paid part-time (in one case, full-time) caregiver. This way, informal caregivers were able to participate in activities outside their home and outside their caregiving role. Notably, these four male spousal caregivers have not suffered from any injuries in the course of providing care and only one complained of headaches. This can be partially explained by the fairly good physical health status of care recipients in this group, who predominantly suffered from memory and cognitive loss rather than chronic health conditions. Their needs differed from those of physically frail care recipients. Dementia caregivers were thus not involved in physically challenging tasks such as lifting or transferring. However, previous research has suggested that dementia caregiving is particularly stressful and the adverse effects of providing care on the caregiver's health were found to be more pronounced in this subgroup (Hooker et al., 2002; McCurry & Terri, 1995; Thomas et al., 2002). Dementia caregivers interviewed in this study felt that having someone else to help them with care provision significantly decreased the caregiving stress. One caregiver said,

of course it does not take the pain away! It's extremely hard on me and our family to see Susan in this state. She's a very intelligent women, sophisticated, ... she used to read and recite Shakespeare and she is a professional, talented piano player. And look at her - she hasn't aged a bit physically. I look at her and see the wonderful person she used to be and then it hits me that she does not see me. ... But Maria [live-in paid caregiver] is a great help! I don't know what we'd do without her. She does all the cleaning and house-keeping, laundry and you name it and she's wonderful with Susan. I can leave the house for bridge or golf without worrying that she'd wander away while I'm gone (Charles, husband, 76).

Three caregivers, who had a home support worker come in for a few hours each week, would have preferred more hours but they did not have the financial resources to purchase additional help.

Study participants were mainly recruited through caregiver support groups and organizations that provide information and services to informal caregivers. Therefore, all of the interviewed caregivers had some knowledge of available community resources and formal services. Thirteen (65%) of the study participants were recruited at the Caregiver Forum, organized by the Caregiver Association of British Columbia. All of these caregivers had attended caregiver support groups. However, their participation in these groups was seen as something temporary, following a specifically challenging episode of care provision. Only two caregivers have been attending these groups on a regular basis for more than a year. Five caregivers (25%) preferred to attend occasional caregiver support events. They lacked the time and energy for regular participation. Other community resources that caregivers found helpful in assisting them with their caregiving responsibilities were the following: church and religious services (n=7 or 35%); community, senior and recreational centres (n=6 or 30%); home support services (n=4 or 20%); respite services (n=2); local library (n=2) and “Meals on Wheels” (n=1). Community and senior centres were found helpful in providing information, workshops and leisure activities. Recreational centres were used for positive coping strategies, such as swimming, aqua fit and exercise programs.

Caregivers were also asked what services they would find helpful. The need for readily available and affordable respite services was voiced almost unanimously (n=16 or 80%). Caregivers complained of long wait periods for respite care, where they were

required to book specific days ahead of time, rather than getting help when most needed. Study respondents expressed their need for more hours of affordable home support services. Four caregivers (20%) were concerned about the “vacuum” they experienced when they assumed the caregiving role or after the care recipient’s diagnosis. They suggested that health and social services for both the care recipient and the caregiver should be well coordinated, so that the caregiver has direction, information and support from the very beginning. Others (n=4 or 20%) talked about their financial strain and worried about their financial stability in the future. They suggested government benefits (n=2) for informal caregivers, free respite care for at least 1-2 weeks per year (n=1) and tax reductions (n=1) for informal caregivers as potential solution.

CHAPTER 7: SUBSTANTIVE THEORY

A novel substantive theme in explaining physical pain and injury in informal caregivers emerged when caregivers were asked about the meaning of physical pain or injury in their lives. Repeatedly, in their first, spontaneous response they expressed their concern for the care recipient's well-being. "Will I be able to keep my husband at home, when my lower back hurts and I cannot help him bathe anymore? Who's going to look after my wife if I'm not strong enough to help her? What if my painful knee gives in while helping mum from bed and she gets hurt?" Only after further prompting were the caregivers able to divert their attention to their own health concerns. However, it appeared that these concerns were considered somewhat irrelevant in the individual's role as a caregiver.

Therefore, more questions were developed in order to explore this theme further. How important is the caregiver's health from their point of view? Will they consider jeopardizing the care recipient's well-being if their own health is at stake? Do other social actors (family, friends, care recipients, health professionals) confirm or contradict this "self-sacrifice" of the caregiver's health? Discovered themes, regularities as well as differences and causal, intervening and contextual factors in the caregivers' experiences of injury and physical pain contributed to the generation of a substantive theory.

According to Glasser and Strauss (1967), comparative analytical methods lead to development of either substantive or formal theory, where substantive theory is seen as a

strategic link in the formulation of grounded formal theory. These two levels of theory differ in terms of the degree of generalizability, and researchers are advised to make an explicit choice of substantive or formal theory prior to conducting the study.

This study was designed as a tool for generating substantive theory in explaining injury and physical pain in informal caregivers. Although substantive theory ascertains a lower level of generalizability, it is a desirable outcome for research in an area where knowledge and previous empirical explorations are sparse. One can hardly assume that initial investigation of unknown phenomena can produce comprehensive understanding, which is required for the formulation of a formal theory. Moreover, generation of a substantive rather than formal theory is more appropriate in this investigation, which was conducted by a novice researcher with limited experience.

The substantive theory generated in this study explains the context of injury and pain in family (mostly spousal) caregivers to frail older adults. Conclusions are drawn with respect to the social process of “attenuating the caregiver’s well-being” while at the same time “accentuating the care recipient’s well-being.” This provides a useful theoretical framework with practical implications for caregiver intervention and support programs. Future studies can use this framework as ground work for further exploration.

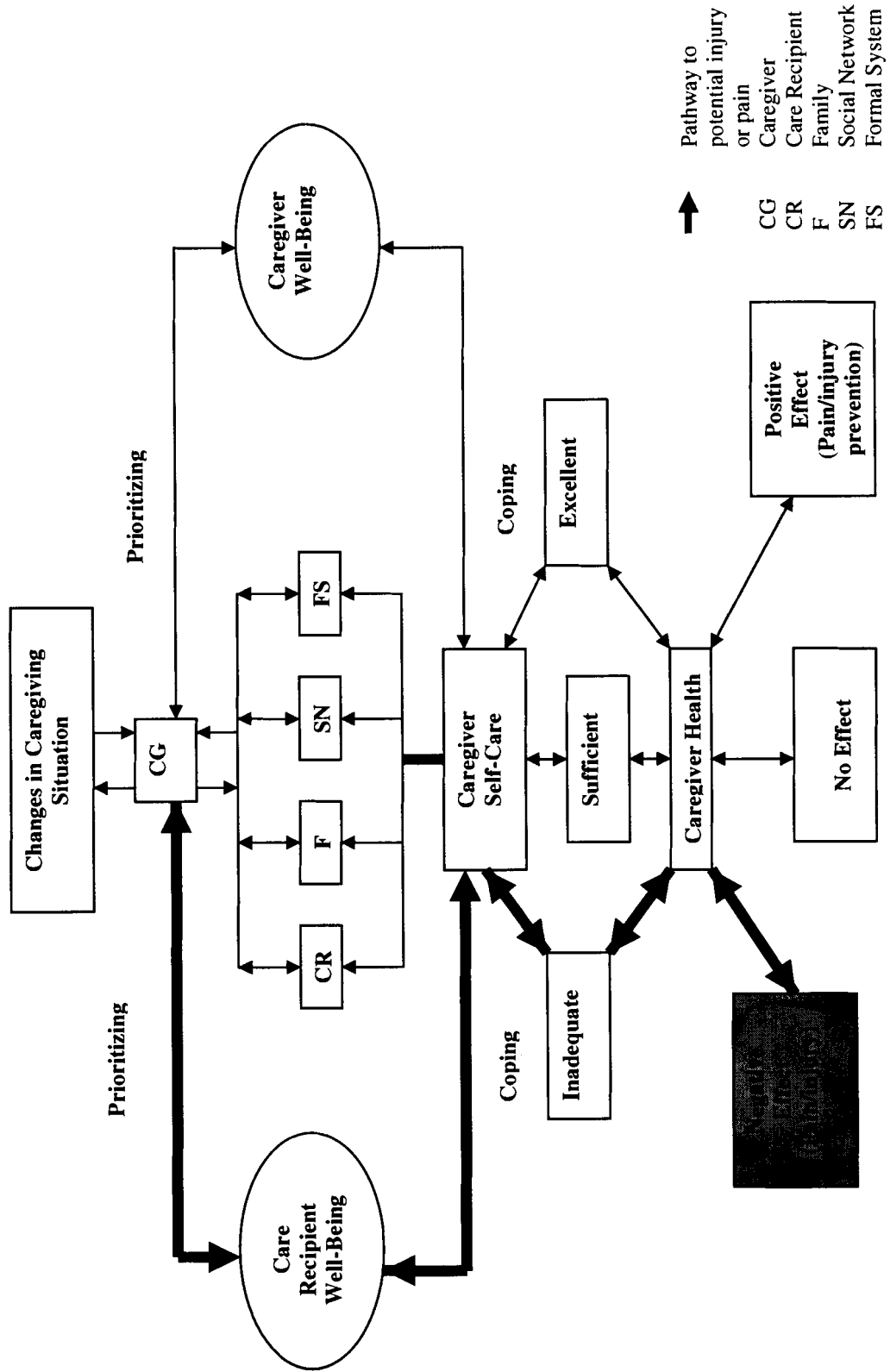
The trends and commonalities described below only apply to the experience of injury and physical pain in a specific subgroup of informal caregivers: predominantly female spousal caregivers to frail older adults. Based on the preceding findings, this chapter elaborates on the contextual factors that are explored in this study. Substantive theory on the primary research question is generated based on these contextual findings. Specifically, this theory addresses the social process of ‘attenuating’ caregivers’ well-

being versus ‘accentuating care recipients’ well-being in the course of providing care to a frail elderly relative.

7.1 Social Process of ‘Attenuating’ Caregivers’ Well-Being While ‘Accentuating’ Care Recipients’ Well-Being

In the course of interviewing informal caregivers who have sustained an injury or suffered from physical pain, it became apparent that caregivers were more concerned about the care recipient’s health and well-being than about their own. Frequently, study respondents minimized the significance of injury and pain in their lives. They focused primarily on the consequences of such health concerns on their care provision and for the care recipient’s well-being. They prioritized the care recipient’s needs, ‘putting aside’ their own needs and compromising their well-being in favour of ‘good care.’ Caregiver health behaviour and preventive practices were specifically affected in this process. The pathway in which injury or physical pain may occur in informal caregivers for frail older adults is summarized in Figure 7.1.

Figure 7.1 The Social Process of Attenuating Caregivers' Well-Being and Accentuating Care Recipients' Well-Being



In the course of providing care, informal caregivers encounter difficulties and changes in the caregiving situation and their everyday life. For example, the care recipient may be having a difficult day with extra pain or discomfort and require more assistance. This adds to the caregiver's responsibilities and could require additional time. Under pressure, the caregiver has to decide what the priorities are and how to meet them. Typically, care recipient's needs 'win,' contrary to the caregiver's needs:

I took the odd day off work, when mum was unwell. Sometimes, I can't get her up in the morning, she's in pain and so stiff! I know that if I didn't oversee her breakfast, she'd just stay in bed and she wouldn't bother eating all day long until I come back to make her supper. And it helps her to move, but she needs to hold on to me for support, she's in pain. She only has me and she never left me home alone when I was a child and I used to be sick quite often (Margaret, daughter, 44).

The process by which caregivers interpret obstacles and assign meaning to them is very complex and involves multiple players. Most importantly, the care recipient, family, social network (friends, co-workers, neighbours, church members) and formal system influence the caregiver's decision making and coping. This is not to say that caregivers discuss every decision with significant others. Social influences shape the caregiving role continuously in the course of providing care. Caregivers seek advice and feedback, recognition and assurance from others. Their own expectations of themselves as caregivers and their understanding of the caregiving role reflect their interpretation of what caregiving means based on cultural and social norms and values. Social influences can be fully expressed and articulated or come in the form of reactions to the caregiver's actions or 'vibes' that the caregiver picks up from others:

They [adult siblings] never said it openly, but it's pretty obvious that they think I should move to mum's house. You just feel it, ... when I try and get them to help out, they have all these excuses - they live too far, their kids have problems, I'm the one who's divorced, no kids and has nothing to do with her life. When I talk to Bev [younger sister] on the phone and I mention that I'm pretty broke, all you hear is silence. Well, she's thinking, move in with mum and stop bragging about it (Heather, daughter, 42).

Social influences, however contradictory, seem to reinforce the caregiver's determination to prioritize the care recipient's health. In this study, some caregivers reported that care recipients were emphasizing the importance of the caregiver's health. One female spousal caregiver said that her husband was

truly wonderful and so grateful and appreciative! He keeps telling me that I should just find a home or hospital for him, that I shouldn't be doing all this hard work, where he can't help me. He worries about my back, because I've never had a strong back (Cathy, wife, 79).

Other caregivers felt that care recipients were undermining the importance of their health:

He [husband] wouldn't let me go. I was determined to spend a week with my sister. This was rubbing on me, I couldn't sleep and I was so close to a nervous breakdown. All that stress! ... Well, I insisted and in the end I went for my little holiday, but did he ever make me feel guilty about this! As if I abandoned him by putting him in a home for a week (Sara, wife, 69)!

However, the result was the same: caregivers strove to enhance or maintain the overall well-being of their loved ones before attending to their own health. Some caregivers assumed the role of the care recipient's 'guardians', making sure that they were taken good care of, even if their 'protection' resulted in family conflict. The majority of the caregivers admitted that they were frequently reminded to look after themselves by their friends or family. However, they felt that they lacked the energy or time for tending to their own health needs.

They all worry about me. My best friend calls every other night and often she'd keep saying that I can't do this on my own. She thinks I should get my son more involved. You're just getting yourself sick, she'd say. But there's too much tension between Jon and my son. So in the end, I'm too tired to go for a walk or exercise, as I used to. (Sue, wife, 74)

Formal systems, in terms of feedback from family physicians, social workers and other professionals, are also influential factors in balancing the care recipient's and caregiver's needs. The caregiver's health is oftentimes overlooked in the focus of healthcare services on the care recipient. Caregivers are used to dealing with healthcare institutions in the role of a 'care manager' or a representative, initiating, overseeing and managing the care recipient's medical care. When faced with a hospital or doctor visit as a consequence of an injury or physical pain, caregivers felt that healthcare institutions were sometimes insensitive to their caregiving role. On the contrary, participation in caregiver support groups or other interventions, provided caregivers with useful tips and tools for self-care and stress relief. However, study respondents admitted that, over time, caregiving responsibilities took over and they found it very challenging to maintain healthy habits and practices.

Interestingly, caregivers emphasized the care recipient's needs and well-being even in the face of an injury and pain. The worst fear that study participants expressed was that of being unable to continue to provide care. Adult daughters in particular attributed very little meaning to injury and pain in their caregiving experience. Their descriptions revealed that injuries and pain were mostly seen as a 'slip', 'clumsiness' or even 'failure' on their part:

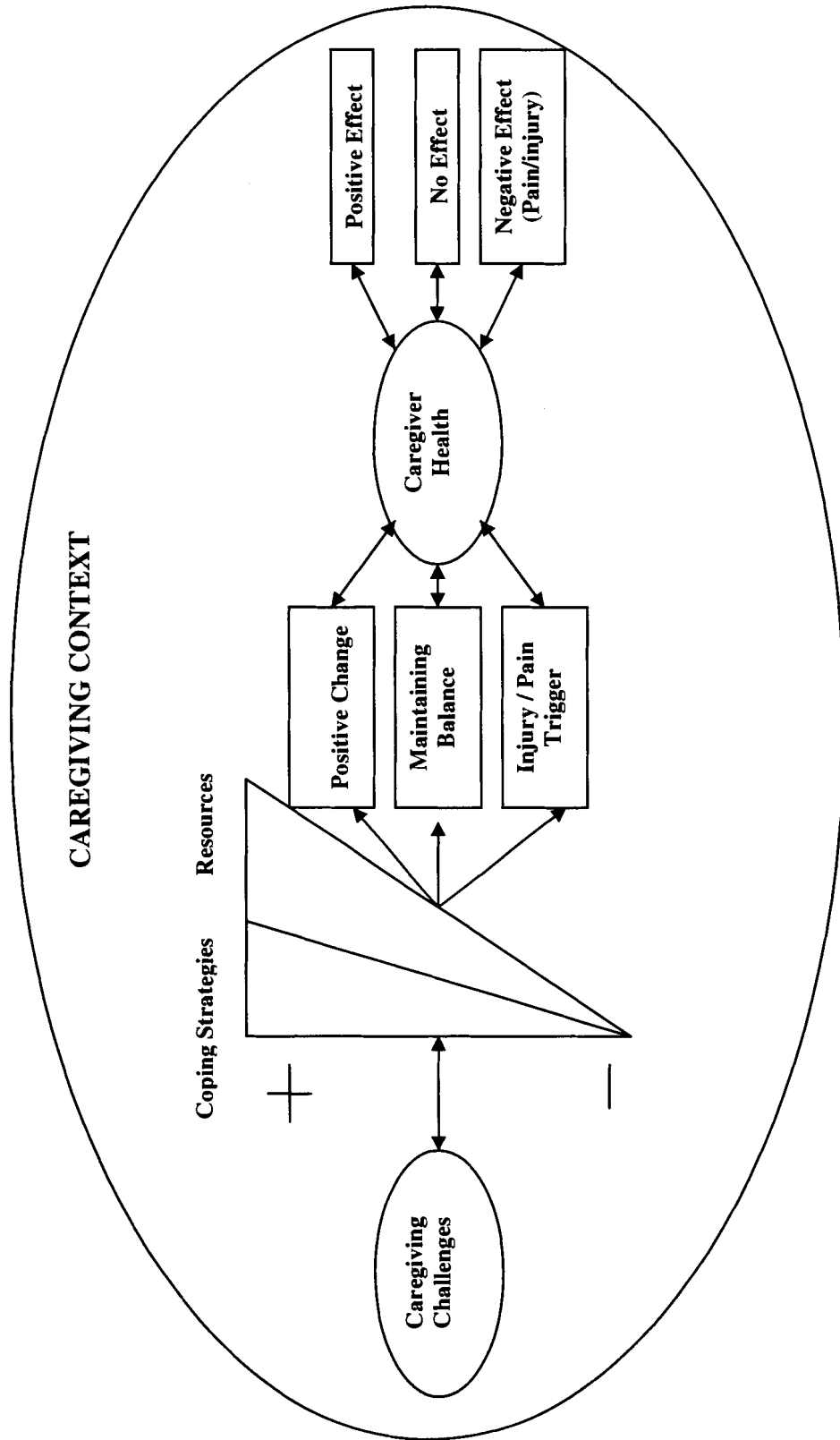
Oh no, I'm not worried about it. You can sprain your ankle walking down the street or jogging. ... It's really nothing. I was kind of stressed out and rushing things with mum, ... and her house is a disaster with all these rugs and dog toys all over the place. I should have been paying more attention! Oh my, what if I tripped helping mum to bed or something! She's so frail; she couldn't take another fall! (Heather, daughter, 42)

Female spousal caregivers were somewhat more worried about their health and expressed a strong fear of falling:

At my age, you don't take falls and bruises easy anymore. Three of my friends ended up in a hospital with a hip fracture and one had to stay in a home, her husband couldn't help her. So yes, I worry a lot about this. I was lucky that I caught myself and I didn't fall. But what if I do next time? We'd both end up in a home, our kids live too far and I wouldn't expect them to go through the trouble of taking care of both of us! (Betty, wife, 84)

Figure 7.2 summarizes the process by which caregiving challenges can produce a negative effect on the caregiver's health. The social aspect of this process, as discussed above, is captured in the overarching nature of the caregiving context. In this figure, caregiver resources and coping strategies are taken into account. Successful coping strategies and adequate resources can provide a 'buffer' against the negative impact of caregiving challenges on the caregiver's well-being. For example, when faced with a sudden deterioration of the care recipient's health in the midst of multiple responsibilities and challenges of work and providing care, one caregiver was able to delegate some of the tasks to a sibling. Thanks to the available family support, this caregiver responded to a caregiving challenge in a positive way. The change in the care recipient's health did not result in an increased extent of care provided by the primary caregiver. On the contrary, a negative event was transformed into a positive change of sharing caregiving responsibilities among family members.

Figure 7.2 The Effect of Caregiving Challenges on Caregivers' Health



Inadequate resources and multiple responsibilities are found to trigger injury and pain for some caregivers. The following verbatim quote illustrates this process:

Things got so much worse, when mum returned from the hospital. I thought she would get better, but suddenly, she couldn't do many of the things that she was capable of before ... It became a full-time job just to help her ... and that does not count cleaning the house, cooking, and laundry. We had conflicts before with my husband about my mum and her living with us. He's got a really busy job, so he doesn't help much in the house. I found myself doing everything--and without complaints--to keep mum at home with us. So you try to do ten things at a time--and of course you're bound to get in trouble. One time I started the fire alarm--I left a pot with boiling water on the stove and went to help mum get ready for bed. It just slipped my mind; I totally forgot that I was cooking too (Laura, daughter, 53).

Similarly, detrimental coping strategies can be hazardous to the caregiver's health. Neglecting one's nutrition, such as irregular meals with low nutritional value, overeating or skipping meals or withdrawing from regular exercise was common among study participants. One male caregiver noted the significant life-style change since household duties had become his responsibility:

Tracy used to be the one pushing me to eat healthy and kicking me out to go for walks with Zack [family dog]. She still helps a bit with the meals but only when I show her exactly what to do, you know, she's very confused and doesn't remember much. ... Me cooking! Well, I've learnt a lot and sometimes our daughter comes by to prepare a nice dinner for all of us ... but it's been downhill since. We definitely don't have that healthy, balanced diet and life-style anymore (Peter, husband, 76)!

Another caregiver complained of her frustration, often resulting in anger when coping with stressful events and caregiving challenges.

I'm feeling pretty drained and empty. ... And terribly angry at Evan for giving up. Some people take tragedies in peace and recover. ... But look at him, just vegetating there, he didn't even try to help the physio[therapist] get him moving. So I'm stuck at home, looking after him and he's totally dependant on me! Which does not have to be, it was his choice to give up! I try to control my anger and usually things are O.K. but when I'm tired and he asks for something that's right in front of his nose, I feel this wave of frustration! And anger makes you pay less attention to what you're doing. ... That's how I tripped last time and almost fell (Vera, 73, wife)

The care recipient's personality, the caregiver - care recipient relationship, family dynamics and available financial resources, among other factors, also seem to mediate the impact of caregiving challenges on the caregiver's health. For example, one caregiver took the precaution of getting respite care to rest, rejuvenate and recover from chronic stress. However, the negative atmosphere in her family counteracted the positive effect of this self-care practice. Upon her return, her adult children, in alliance with the care recipient resented her for placing the father in a 'nursing home.' Family conflict further aggravated the stress and burden experienced by this caregiver. Moreover, she felt reluctant to apply for respite in future for the fear of another family conflict.

In summary, informal caregivers, overwhelmed by their caregiving responsibilities, tend not to attend to their own health needs and neglect their self-care. In the social process of *attenuating caregivers' well-being and accentuating care recipients' well-being*, family members caring for frail elderly relatives commonly withdraw from or restrict the amount of time spent engaging in social and leisure activities and hobbies. Moreover, caregivers admit to having irregular eating habits, forgetting to take their own medications and not getting enough rest. They are less motivated to exercise and often choose passive rest, such as watching TV. This tendency in itself does not necessarily result in the experience of an injury or physical pain. However, inadequate resources and

detrimental coping strategies alongside additional caregiving challenges and stressful events increase the risk for adverse health outcomes, including injury and pain.

When caregivers experience an injury or physical pain, they focus on their own physical health for a limited period of time, while the symptoms are prevailing. After that, caregiving responsibilities and the care recipient's needs overrule the caregiver's self-care. However, injuries can also initiate positive change. For example, caregivers reported more caution in performing caregiving tasks and improved care planning in an attempt to avoid additional injuries. These trends, commonalities and differences have many practical implications for caregiver interventions and health promotion programs, which will be discussed in the next chapter.

CHAPTER 8: DISCUSSION

The current study explored the experience of physical pain and injuries in informal caregivers to frail older adults. This is an area that has not yet received much attention in the caregiving literature. Previous research was reviewed, relating to the extent of eldercare provided informally, mental and physical health outcomes of informal caregiving, injuries in formal caregivers and finally physical pain and injuries in informal caregivers. The following research question was developed, based on the literature review: "What is the context in which physical pain and injuries are experienced in informal caregivers to older adults?" Six sub-areas guided the investigation: caregiving situation and physical pain and injuries in informal caregivers; consequences of physical pain and injuries to informal caregivers, problematic aspects of the caregiving experience, positive aspects of the caregiving experience and their role in explaining physical pain and injury, caregiver coping strategies, and personal, social, economic and community resources utilized by informal caregivers in dealing with physical discomforts and preventing injuries. Study findings guided the generation of a substantive theory. This theory relates to the social process of "attenuating the caregiver's well-being while accentuating the care recipient's well-being". It was a common tendency among study participants to 'put aside' their own needs and to assign an inferior value to injury and pain and their own health as compared to the care recipient's health. The caregivers' neglecting of their health and well-being and their detrimental health behaviors need to be addressed in future caregiver interventions.

The experience of physical pain and injury differed across the three participant subgroups (male spousal caregivers, female spousal caregivers, and adult daughters). Gender differences in the caregiving experience have been reported in previous studies (e.g. Gallicchio et al., 2002; Navaie-Waliser et al., 2002; Pinquart & Sörensen, 2006). In this study, commonalities within the subgroups and differences between them cannot be solely attributed to gender. The majority of male spousal caregivers provided care to their wives with Alzheimer's disease, as compared to the rest of the sample, providing care to physically frail elderly relatives. Care recipients with dementia did not suffer from any major chronic physical health conditions or physical function limitations. Therefore, dementia caregivers were not involved in physically challenging care tasks with an increased risk for injury and physical pain. One difference that could be explained by gender relates to the fact that male spousal caregivers had sufficient resources to hire professional help. This could reflect gender differences in financial resources, especially in this older generation.

Female spousal caregivers were especially vulnerable to injuries and physical pain. Their physical discomfort was more severe and had more pronounced consequences on their overall well-being. This could be due to the fact that they lived in the same household with the care recipient and provided more hours of care per week. Consequently, they were more likely to report caregiver burden. Previous research has found that cohabitation with the care recipient is associated with increased stress in the caregiver (Herlitz & Dahlberg, 1999). Moreover, wives caring for their frail spouses are more likely to report that their own health status was fair or poor as compared to adult daughters. Respondents in this subgroup found providing care physically challenging and

draining, which can be explained by their own deteriorating health and functional status. Additionally, the care recipient's condition played its role. Female spousal caregivers cared for husbands with stroke or heart disease with relatively high care needs. For example, they would typically find themselves supporting their husbands while walking them from one place to another, which leads to a considerable strain on the caregiver's back and muscles. Again, we cannot draw conclusions from comparison to male spousal caregivers. When providing care to a frail wife, they may be as vulnerable to injuries and physical pain as were the female spousal caregivers.

It is difficult to isolate events or factors that may have caused the injuries and pain in study respondents. The caregiving experience is a continuous, complex process and other factors from outside the caregiving situation may have contributed. Moreover, the caregivers were reporting injuries retrospectively. Therefore, they could not always clearly identify the causal factors. However, study participants who suffered from injury or physical pain, typically attributed those events to the physically challenging nature of their work alongside with chronic stress and lack of concentration due to fatigue or multiple responsibilities. Adult daughters, in particular, complained of multiple responsibilities including work and looking after other family members. They were commonly trying to get things done as fast as possible. This could have caused some of the tension between the caregiver and the care recipient that was reported by adult daughters. As previously discussed, in some cases, adult daughters reported that the care recipient was unwilling to help or refusing to be helped. Facing the time constraint of multiple responsibilities, these caregivers chose to 'force' the care, which in one case resulted in the caregiver severely injuring her knee. This is an important finding to

consider in designing caregiving interventions and also in preventing elder abuse and neglect.

The important role of social support in alleviating caregiving stress and burden has been discussed in previous studies (e.g. Brummett et al., 2006; Grant et al., 2000; Mittrani et al., 2006). Therefore, it is not surprising that study participants stressed the importance of their families and friends in their caregiving experience. Phoning friends and family was a common strategy utilized by caregivers in face of the caregiving challenges. On the contrary, lack of support from family or friends and family conflicts added significantly to the caregiver's feelings of burden. Again, this is an important factor to consider in designing caregiving interventions.

Another important factor relates to negative coping strategies reported by the study participants. The majority of them admitted that they had been neglecting their own health to some extent. Moreover, many caregivers said that they withdrew from their hobbies and leisure activities. This way, some of the venues they had typically used for stress relief were missing in their lives and their social network was also somewhat restricted. Other researchers have reported detrimental health behaviors and inadequate time for leisure activities in informal caregivers (Carter et al., 1999; Connel & Gallant, 1999). Findings from this study further stress the significance of addressing this issue in informal caregivers. This is especially important knowing that detrimental health behaviors, such as inadequate sleep, may have contributed to injuries and physical pain experienced by the study participants. For example, three out of the four injured adult daughters caring for their frail parents said that they were tired from lack of sleep when the injury occurred.

Findings from this study provide the foundation for a substantive theory, describing the social process of 'attenuating' the caregiver's well-being while 'accentuating' the care recipient's well-being. This theory adds significantly to our limited understanding of how injuries and physical pain occur in informal caregivers. A possible pathway to adverse effects of caregiving on the caregiver's health was summarized in Figure 7.1. Previous studies support the finding that informal caregivers tend to neglect their own needs in the course of attending to the care recipient's needs (e.g. Lipkowitz, 1992). It seems that caregiving role sometimes transforms into a 'service', or almost a self-sacrifice, intentionally or unintentionally, as the caregiving tasks require increasing time and energy on the caregiver's side. Caregivers carry on with physically and emotionally draining tasks even in the face of their own injury and physical pain. The predominant motivation behind their unceasing heroic work seems to be drawn from their belief that the care recipients are better cared for at home by their loved ones than in formal institutions. It would be interesting to explore this notion from the care recipient's point of view in future research. This study further emphasises the important role that family members play in the well-being of frail older adults who would otherwise require formal services.

Importantly, this study shows that informal caregivers are vulnerable and prone to injuries and physical pain that may limit their ability to provide care. Continuous overlooking of the caregiver's health may result in their future health problems. They may then have to rely more on the healthcare system. Therefore, short-term savings from leaving eldercare in the hands of family members without adequately supporting them could result in increased healthcare costs in the future. The practical implications of the

study findings for caregiver interventions and injury prevention programs are discussed below.

8.1 Practical Implications

In order to protect the caregiver's health, many factors need to be taken into account. Most importantly, injuries and physical pain should be prevented, rather than treated. Informal caregivers would benefit from education and training relating to injury and pain triggers and hazardous situations. Health practitioners or social workers in healthcare institutions that provide services to the care recipient should identify primary caregivers and link them to information and health promotion programs. This way, caregivers can learn about safe transitioning and lifting techniques and prevent muscle strains and back injuries.

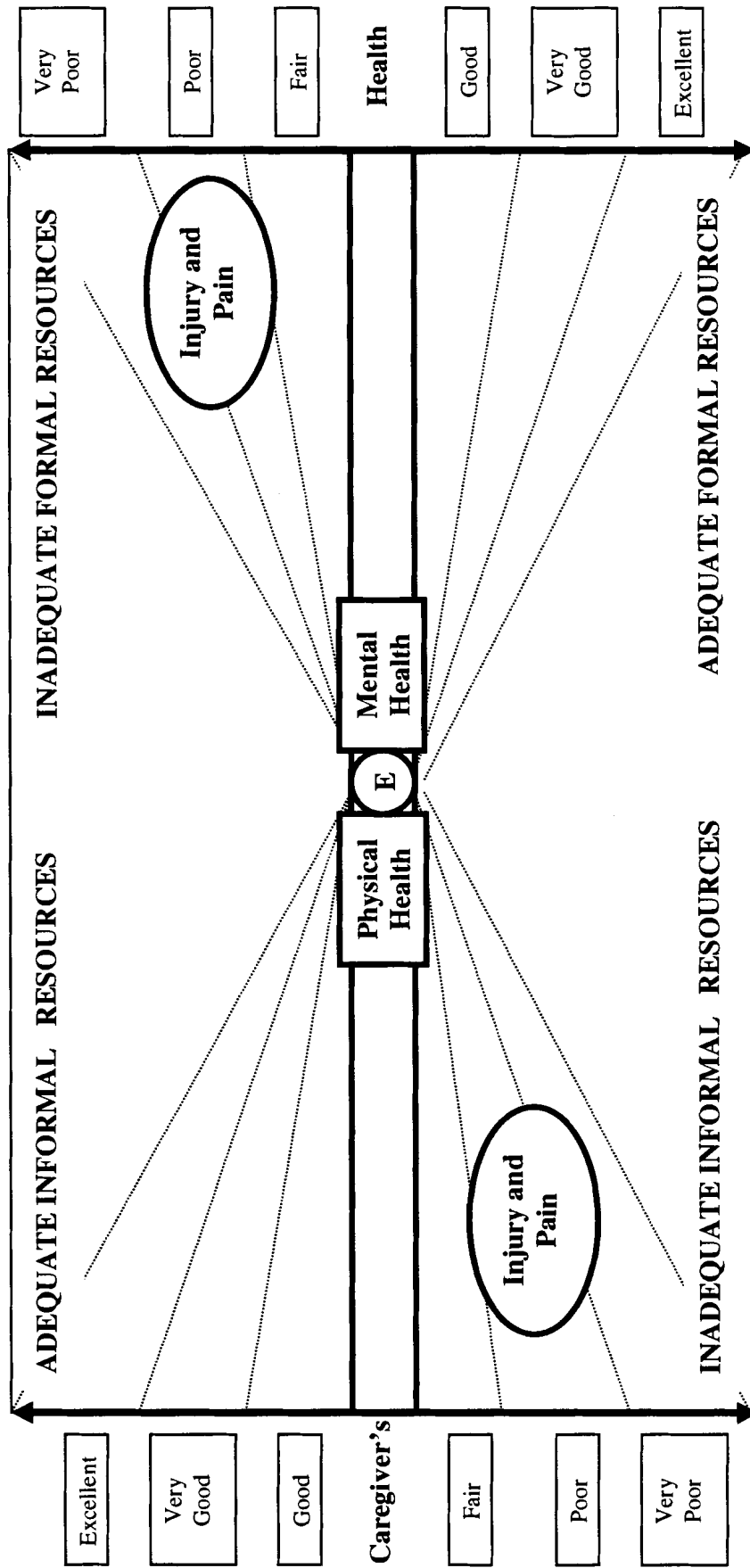
Another potential way of preventing injuries and pain can be through home assessments and modifications, geared towards removing injury triggers in the environment. Such assessments and information sessions can be administered by volunteers, for example students or peer-counsellors trained in injury prevention. There are some beneficial programs in place for professional healthcare workers that could be expanded to include informal caregivers. For example, Organizational Health and Safety Agency for Healthcare in British Columbia is active in preventing workplace injuries in healthcare settings.

Exercise programs geared towards informal caregivers would be very beneficial. Such programs will require flexibility and should provide simple routine that can be followed in groups (for example caregiver support group) as well as individually at the

caregiver's home. Gentle and moderate muscle strengthening, posture and balance training could prevent some injuries and falls by keeping the caregiver in a healthy physical and mental condition. Moreover, exercise programs at home can be modified to include some light stretching and strengthening for the care recipient (such as exercising while seated in a chair or a wheel-chair). In this way, exercise can become a regular routine both for the caregiver and the care recipient, adding more fun and motivation to this prevention strategy.

Though there are formal services available for informal caregivers, those interviewed in this study often said that they were not always affordable or convenient. As outlined in Figure 8.1., some individuals may be more resourceful. For example, they may have a higher income, better health to start with, more friends and family members to rely on, etc. Caregivers who have inadequate informal resources will need more formal support. Caregiver interventions should aim at providing a buffer to the negative effects of caregiving on the individual's health. Figure 8.1. conceptualizes this as 'E', an ideal state of caregiver's health equilibrium, where the effects of providing care on the caregiver's physical and mental health are balanced and no 'damage' is done. Notably, caregivers may have pre-existing health conditions that cannot be reversed. They are also aging and some health and functional changes in this process cannot be prevented. Thus the state of 'caregiver's health equilibrium' is an ideal theoretical state that cannot be fully achieved in the longer term. However, caregiver interventions could possibly yield positive effect in not only maintaining but also improving the caregiver's health and preventing potential injuries and pain.

Figure 8.1 Balancing Informal and Formal Resources for the Caregiver's Health Equilibrium



E – Health Equilibrium (No significant effect of caregiving on the caregiver's health)

The study findings show the importance of an individual approach to caregiving interventions. Each caregiving situation is different as are the caregivers. Though they face similar challenges, some attribute more meaning to a certain stressor, while others are able to cope with the same stressor adequately. Some caregivers thrive in social environments and they find interventions such as caregiver support groups very helpful. Others prefer a more individual approach. Their needs may be better met by one-to-one counselling sessions, where they could express their concerns and receive meaningful feedback from a skilled therapist with experience in caregiving situations. A wider variety of caregiver support services are required in order to protect the health of informal caregivers and maintain their ability to provide care. Such services need to respect the caregivers' time restrictions and provide flexible times and ways of accessing them. Also, the caregiver may have nobody else to take over care responsibilities when they attend an intervention. Offering alternate intervention venues, such as telephone support groups; a twenty-four-hour caregiver help line; or internet-based interventions, could offer a more viable solution.

The study participants complained about the lack of readily available and affordable respite services. Respite is required in order to provide the caregiver with a pause in caregiving responsibilities where he or she can rejuvenate and recharge and attend to his or her own needs. This does not always need to mean placing the care recipient in a care facility. Volunteers could provide short-time respite services. As little as a few hours per week for a 'friendly visit' would give the caregiver a regular time to step out of the house and out of the caregiving responsibilities. Involving family members and friends and sharing the caregiving tasks among them opens another venue for respite.

Unfortunately, caregiver needs sometimes seem to receive inadequate attention in the network of healthcare and social services that focus on the care recipient. The caregiver and the care recipient need to be treated as a dyadic entity. When discussing the care recipient's health and care needs with general practitioners, social workers, case managers and other healthcare and social services professionals, the caregiver's needs and health ought to receive comparable attention. Ideally, caregiver support services would start as soon as the caregiver assumes his or her caregiving role, if not prior to that. This should include information on what to expect in the course of providing care, what resources are available for the care recipient and for the caregiver, and how to efficiently attend to the care recipient's as well as the caregiver's needs. Caregivers providing physically challenging care need to be trained in safe lifting and handling positions in order to avoid awkward and twisted postures resulting in back strains and injuries. Furthermore, both the caregiver's and care recipient's overall health status should be monitored on a regular basis. This way, any occurring adverse effects of caregiving on the caregiver's health can be attended on time while they still may be reversed.

Some respondents complained of family conflict and inadequate support from other family members. Therefore, family-based interventions would be extremely beneficial. These interventions they would be especially helpful in the initial stage, when families are faced with making a decision on who is to be the primary caregiver and what will be the role of other family members in the care provision. A skilled mediator or facilitator could monitor the family dynamics and guide the families in finding optimal ways of caring for their loved ones without burdening solely one family member.

Finally, caregiver interventions need to be proactive and reach out rather than expect the caregivers to seek and approach them. Caregivers are typically caught in the middle of their responsibilities and tend not to access services until they feel very stressed or burdened. Successful interventions should reach the caregiver early in the process and they should be available continuously in the course of providing care. This way, caregivers will have the opportunity to learn about the importance of their own health right from the start. Regular feedback and appraisal would be very beneficial in the caregiver's maintaining of healthy behaviors. In conclusion, a wider range of affordable interventions and support services is required in preventing injury and alleviating pain in informal caregivers. Successful programs will be flexible and sensitive to individual differences among caregivers and care recipients.

8.2 Study Limitations

In drawing conclusions from the study findings, the scope and design of this study must be taken into account. This is a sample of predominantly white, female caregivers to frail older adults with specific conditions - heart disease, stroke, arthritis, hip fracture, multiple sclerosis and severe arthritis. At the initial stage of this research, caregivers to older adults with Alzheimer's disease were interviewed. Given the fact that injury and physical pain did not emerge as an important concern in this subgroup, further investigation focused solely on those caregivers who have sustained an injury or suffered from physical pain. Potential study participants other than those with injury or pain were deemed ineligible. Therefore, the study findings reflect the experience of purposely selected informal caregivers. The frequency of injury and physical pain in this sample is not representative of informal caregiving population.

The sample has some further limitations that have to be acknowledged. The criterion of English proficiency excluded a significant proportion of informal caregivers with diverse ethnic backgrounds. For example, recent immigrants or ethnic families not proficient in English were unable to participate. A contextual analysis and exploration of cultural issues and differences would have been very beneficial.

Moreover, this is a convenience sample of caregivers who have used or have at least contacted some support organizations listed in the previous section. This subset is therefore likely to be more aware of support services and available resources than other caregivers. Some have received training aimed at enhancing their caregiving competencies or they attended regular caregiver support groups. This could have biased the sample in two possible ways. Firstly, convenience samples in previous studies have been criticised for unusually increased prevalence of depressive symptoms or perceptions of burden. It is assumed that caregivers only seek out service when they feel considerably strained by their caregiving responsibilities. Secondly and conversely, the regular utilization of services by these caregivers may have exposed them to more venues for social and emotional support. This could possibly buffer some of the adverse effects of caregiving challenges on their overall well-being.

This study has several limitations that need to be acknowledged. First, as previously discussed, these findings are based on a small convenience sample (N=20) of female and male spousal caregivers and adult daughters predominantly caring for their physically frail elderly relatives. Other subgroups of caregivers could have added significantly to the exploration of injury and physical pain, as well as caregivers from diverse cultural backgrounds. Also, the socio-economic status of the study respondents

was somewhat higher than would have been ideal. It would be beneficial to explore how those with limited financial and material resources and lower education cope with caregiving challenges and with potential injuries and pain. Notwithstanding these sample restrictions, caregivers interviewed in this study provided a variety of caregiving situations with differences in care recipient characteristics and caregiver resources and coping strategies. Data collected in this research was therefore very rich and diverse.

Secondly, injuries and pain reported in study participants in most cases did not occur immediately before the time of the interview. Therefore, caregivers had to recall the circumstances around the injury retrospectively. This could have compromised the accuracy of the collected data. Ideally, caregivers should be followed on a long-term basis and potential injuries and pain recorded and interpreted at the time they occur. However, the majority of injuries or physical pain experienced by the study respondents were fairly recent (mean time from the event=80 days) with the maximum time span from sustaining an injury or experiencing physical pain being 4.5 months. It can be thus assumed that caregivers were still able to recollect these events fairly accurately.

In addition, physical pain reported by the respondents was not measured objectively. The severity or types of pain described in this study are based on the subjective experience of each individual caregiver. This may have caused some inconsistencies in categorizing physical pain. For example, a painful experience deemed as severe by one caregiver could have been described as moderate by another. However, this study strived to explore injuries and physical pain from the caregiver's perspective. Therefore, it was a priority to interpret physical pain as experienced by the caregiver.

Finally, only short-term, immediate effects of injury and pain on the caregiver's well-being were examined. Consequences of such events may be more pronounced in a longer period. A longitudinal study design would be ideal in determining the full extent in which injury and pain impact the caregiver's and care recipient's well-being. This provides opportunities for future research to build on this study and overcome some of the limitations discussed in this section.

8.3 Recommendations for Future Research

This study brings attention to a very important aspect of the caregiving experience that has not been yet explored in the gerontological literature. More research is required in order to provide findings that can be generalized and used for guiding health promotion programs. Additional subgroups of informal caregivers should be included, such as adult sons and other male and female relatives and friends caring for physically frail older adults.

Regrettably, this research did not yield sufficient numbers of participants to support comparisons within different groups of informal caregivers. It would be beneficial to compare the experience of injury and physical pain among caregivers for older adults with specific health conditions. For example, are 'stroke victim' caregivers more likely to get injured or suffer from physical pain as compared to those caring for someone with arthritis or diabetes? What are some of the similarities and differences among these caregiver groups?

The study findings suggest that injuries and physical pain are not of a concern for mild dementia caregivers. The demands and challenges of dementia caregiving seem to

initially cause emotional rather than physical pain. However, this finding cannot be generalized due to the limited sample size. Therefore, future research of injury and pain in dementia caregivers based on larger samples and using longitudinal design would be very beneficial.

Future studies should use not only subjective but also reliable objective measures of the type and extent of the injury and physical pain, in order to provide comparable results. Ideally, informal caregivers should be involved in such research continuously throughout their caregiving experience and tested on a regular basis by a general practitioner. Caregivers should become study participants when they assume their caregiving role, rather than later in the course of providing care. This way, researchers will be able to determine, whether informal caregivers are at a higher risk for injury at the beginning of their caregiving career, when they are adjusting to their tasks and responsibilities, or later on, when the long term effects of chronic stress may become more pronounced. Importantly, control groups of demographically matched non-caregivers should be included in future studies. This will help determine the extent to which injuries and physical pain are a result of providing care rather than naturally occurring events in the life-course. For example, several female spousal caregivers in this study described their injury as a fall. However, falls are relatively common in older adult populations, especially in elderly women. Even though falls in this study were triggered by caregiving tasks, it may be possible that the injured caregivers were prone to falls for other reasons as well, such as due to balance impairments. Future studies can control for such factors by including control groups.

The scope of this study did not allow for investigating other factors in explaining physical pain and injury, such as neglect and abuse. There is a growing body of literature relating to elder abuse and neglect both in healthcare institutions and home settings. This is another important area where further knowledge would be beneficial in preventing injury and pain in both the caregiver and the care recipient.

Findings from this study provided grounds for the substantive theory of "attenuating the caregiver's well-being while accentuating the care recipient's well-being in the course of providing care." Further research is required in order to ascertain that this is indeed a common trend and a potential pathway to injury and physical pain in informal caregivers. It would be interesting to see the health outcomes of providing care in those who attend adequately to their own health needs as well as those of the care recipient. Are they more likely to be in a good health than their 'self-sacrificing' peers?

In addition, other contextual factors should be explored, such as the role of ethnicity and culture in the experience of injury and pain in informal caregivers and many other factors (e.g. income and socio-economic status, living arrangements, age, gender, potential conflicts between the caregiver and care recipient, etc.). Caregivers from certain cultural or ethnic backgrounds may be more likely to receive support from other family members or from church and community members, which could affect the way they experience care provision and potential injuries and pain. Finally, a more thorough investigation of the injury and pain triggers is required. Hopefully, this will pave the way for improved prevention of future injuries and physical discomfort among informal caregivers to older adults.

APPENDIX

Interview Guide

**THIS PAGE WITH YOUR CONTACT INFORMATION WILL BE KEPT
SEPARATE FROM THE QUESTIONNAIRE.
YOUR RESPONSES ARE CONFIDENTIAL AND ANONYMOUS. THEY WILL
ONLY BE USED FOR THE PURPOSE OF THIS STUDY.**

Your Name

Phone Number

Your Contact Address

E-Mail Address

Where did you hear about the study?

Would you like your name entered in a draw to win \$50?

YES _____ NO _____

Would you like to be contacted in the future with information about other studies?

YES _____ NO _____

INTERVIEW DATES AND LOCATION

1st Interview

Date and Time _____

Location _____

2nd Interview

Date and Time _____

Location _____

1. Socio-Demographic Background

1.1. Caregiver's Age _____

1.2. Care Recipient's Age _____

1.3. Caregiver's Gender

MALE FEMALE

1.4. Care Recipient's Gender

MALE FEMALE

1.5. Caregiver's Marital Status

- SINGLE NEVER MARRIED
- MARRIED WIDOWED
- DIVORCED SEPARATED

1.6. Caregiver's Highest Achieved Education

- GRADE 8
- SOME HIGH SCHOOL
- HIGH SCHOOL DIPLOMA
- SOME COLLEGE / UNIVERSITY
- UNIVERSITY DEGREE

1.7. Caregiver's Ethnic Background

1.8. Caregiver's Employment Status

- Employed / Self Employed
 - Part-time
 - Full-time
- Retired Never Employed

1.9. Caregiver's Occupation

(Current or before retirement/
marriage)

1.10. What is your current religious affiliation? (church, denomination)

_____ NONE (spiritual) NONE AT ALL

1.11. Regardless of whether you attend religious services, do you consider yourself:

NOT AT ALL RELIGIOUS SOMEWHAT RELIGIOUS
 MODERATELY RELIGIOUS VERY RELIGIOUS

1.12. Regardless of whether you attend religious services, do you consider yourself:

NOT AT ALL SPIRITUAL SOMEWHAT SPIRITUAL
 MODERATELY SPIRITUAL VERY SPIRITUAL

1.9. Number of Children _____

1.10. Dependant Family Members _____

(Family members other than the care recipient that the caregiver is taking care of)

1.11. Care Recipient's Relationship To The Caregiver

_____ SPOUSE
_____ PARENT
_____ GRANDPARENT
_____ FATHER/MOTHER IN LAW
_____ SIBLING
_____ FRIEND
_____ OTHER (Specify) _____

Annual Household Income (before taxes)

- Less than \$25,000
- \$25,001 – \$50,000
- \$50,001 - \$ 75,000
- \$75,001 - \$100,000
- Over \$100,000

2. Health-Related Characteristics of the Caregiver

2.2. Self-Rated Health Status

- Poor
- Fair
- Good
- Very Good
- Excellent

2.3. Chronic Health Conditions

2.4. Have you experienced any serious health conditions or injuries in the past 10 years?

If yes, please specify:

3. Health-Related Characteristics of the Care Recipient

3.1. Care Recipient's Overall Health Status:
(Caregiver's Rating)

- Poor
- Fair
- Good
- Very Good
- Excellent

3.2. Chronic Health Conditions (List)

3.3. When was your relative diagnosed with dementia? _____

3.4. Stage of Alzheimer's Disease

- EARLY MILD ADVANCED

4. Context of Injury and Pain

Caregiving Experience and Relationship

- 4.1. Do you live in the same household with the care recipient?
- 4.2. How long have you been providing care for?
- 4.3. What are your responsibilities (what tasks do you perform)?
- 4.4. How many days a week do you provide care?
- 4.5. How many hours on average a week?
- 4.6. Who else is helping you with the care provision and to what extent?
- 4.7. What other responsibilities do you have (work, children, grandchildren)?
- 4.8. How would you describe your relationship with ...?

Negative And Positive Aspects of Caregiving

- 4.8. What is difficult, challenging or negative in the caregiving experience?
- 4.9. What are some of the positive aspects of your caregiving experience?

Injury/Pain Experience

- 4.10. Have you suffered an injury in the course of providing care?
IF YES:
 - 4.10.1. Did you get injured while providing care or somewhere else?
 - 4.10.2. What happened? How did the injury occur?
 - 4.10.3. Who else was around?
 - 4.10.4. During what activity did the injury happen?
 - 4.10.5. What was the care recipient doing when the injury happened?
 - 4.10.6. Where did the injury occur?
 - 4.10.7. Were there obstacles/hazards in the physical environment involved in the injury?
 - 4.10.8. Was anything different on the day it happened?
 - 4.10.9. What does the caregiver think about the injury and the way it happened?

4.11. What is your experience with pain in the course of providing care (shoulders, neck, headache, etc.)?

4.11.1. What area is/was affected?

4.11.2. How severe is/was the pain?

4.11.3. How long did the pain last?

4.12. What about emotional pain, distress?

4.13. How do you feel about injury and pain while providing care?

4.14. What do injury and pain mean to you as a caregiver?

5. Effect of Injury and Pain on the Caregiver

(Caregivers who reported injury/pain)

5.1. What is different in your life after the injury or with the experience of pain?

5.2. In what way pain did injury and/or pain affect the care provision?

5.3. How did it affect your other daily activities?

5.4. How did it affect your spouse/father/etc. (care recipient)?

5.5. What other changes did it bring (positive, negative)?

6. Caregiver Coping Strategies

(Positive and negative)

6.1. How do you cope with the challenges of caregiving?

6.2. What helps you to keep on going while taking care of your spouse/father/etc. (care recipient)?

6.3. How do you “recharge your batteries” in the course of providing care?

6.4. How do you cope with pain/injury?

6.5. How do you deal with emotional pain and distress in the course caregiving?

7. Caregiver Resources

Available Resources (material, financial, personal, training/skills/knowledge, family and social support, spiritual, formal services and support)

- 7.1. What help is available for you while providing care?
- 7.2. What resources do you utilize?
- 7.3. What helps you in your caregiving responsibilities?
- 7.4. What resources did you have prior to caregiving that you use now?
- 7.5. What resources did you acquire in the course of providing care?

Required Resources

- 7.6. What resources would help you in care provision?
- 7.7. What would help you deal with injury?
- 7.8. What would help you deal with pain?
- 7.9. What would help you deal with emotional pain?
- 7.10. How can injuries and pain be prevented?

Comments

REFERENCE LIST

- Acton, G.J. (2002). Health-promoting self-care in family caregivers. *Western Journal of Nursing Research*, 24(1), 73-86.
- Adams, B.N. & Sydie, R.A. (2002). Contemporary sociological theory. Thousand Oaks, CA: Pine Forge Press.
- Anderson, C.S., Linto, J. & Stewart-Wynne, E. (1995). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke*, 26, 843-849.
- Ayres, M.M. & Woodtli, A. (2001). Concept analysis: abuse of ageing caregivers by elderly care recipients. *Journal of Advanced Nursing*, 35(3), 326-334.
- Baumgarten, M., Batista, R.N., Infante-Rivard, C., Hanley, J.A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family member caring for an elderly person with dementia. *Journal of Clinical Epidemiology*, 45, 61-70.
- Berg-Weger, M. & Tebb, S.S. (2004). Conversations with researchers about family caregiving: Trends and future directions. *Generations*, 27(4), 9-15.
- Blumer, H. (1969). Symbolic interactionism: perspective and method. Englewood Cliffs, N.J.: Prentice-Hall.
- Boland, D.L. & Sims, S.L. (1996). Family caregiving at home as a solitary journey. *Journal of Nursing Scholarship*, 28(1), 55-59.
- Brown, A.R. & Mulley, G.P. (1997). Injuries sustained by caregivers of disabled elderly people. *Age and Ageing*, 26, 21-23.
- Brulin, C., Gerdle, B., Granlund, B., Hoog, J., Knutson, A. & Sundelin, G. (1998). Physical and psychosocial work-related risk factors associated with musculoskeletal symptoms among home care personnel. *Scandinavian Journal of Caring Sciences*, 12(2), 104-110.
- Brulin, C., Winkvist, A. & Langendoen, S. (2000). Stress from working conditions among home care personnel with musculoskeletal symptoms. *Journal of Advanced Nursing*, 31(1), 181-189.
- Brummett, B.H., Babyak, M.A., Siegler, I.C., Vitaliano, P.P., Ballard, E.L. et al. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychology*, 25(2), 220-225.
- Bumagin, V.E. & Hirn, K.F. (2001). *Caregiving: A guide for those who give care and those who receive it*. New York: Springer Publishing Company.

- Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, *150*(6), 899-913.
- Campbell, L.D. & Martin-Mathews, A. (2000). Caring sons: Exploring men's involvement in filial care. *Canadian Journal on Aging*, *19*(1), 57-79.
- Cannuscio, C.C., Jones, C., Kawachi, I. et al. (2002). Reverberatons of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health*, *92*(8), 1305-1311.
- Caron, C.D., Griffith, J. & Arcand, M. (2005). Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal of Applied Gerontology*, *24*(3), 231-247.
- Carter, M.J., Nezey, I.O., Wenzel, K. & Foret, C. (1999). Leisure education with caregiver support groups. *Activities, Adaptation & Aging*, *24*(2), 67-81.
- Cattanach, L., & Tebes, J.K. (1991). The nature of elder impairment and its impact on family caregivers' health and psychological functioning. *Gerontologist*, *31*, 246-255.
- Chappell, N.L. & Binstock, R.H. (1991). Caregiving research and more caregiving research: What good is it? *Gerontologist*, *31*(4), 567-570.
- Chumbler, N.R., Pienta, A.M. & Dwyer, J.W. (2004). The depressive symptomatology of parent care among the near elderly. *Research on Aging*, *26*(3), 330-351.
- Chwalisz, K. (1992). Perceived stress and caregiver burden after brain injury: a theoretical integration. *Rehabilitation Psychology*, *39*, 29-48.
- Connel, C.M. & Gallant, M.P. (1999). Caregiver health behaviour: Review, analysis, recommendations for research. *Activities, Adaptation & Aging*, *24*(2), 1-16.
- Coyne, A., Reichman W. & Berbig, L.J. (1993). The relationship between dementia and elder abuse. *American Journal of Psychiatry*, *150*, 643-646.
- Creswell, J.W. (1998). *Qualitative Inquiry and Research Design. Choosing Among Five Traditions*. Thousand Oaks, CA: Sage Publications.
- Cutcliffe, J.R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, *31*(6), 1476-1485.
- Denzin, N.K. & Lincoln, Y.S. (Eds.).(1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- Descombe, M. (2003). *The Good Research Guide: For Small-Scale Social Research Projects*. Buckingham: Open University Press.
- Donelan, K., Hill, C.A., Hoffman, C. & Scoles, K. (2002). From the field: Challenged to care: Informal caregivers in a changing health system. *Health Affairs*, *21*(4), 222-231.

- Fassinger, R.E. (2005). Paradigms, praxis, problems, and promise: Grounded theory in counselling psychology research. *Journal of Counselling Psychology, 52*(2), 156-166.
- Fuller-Jonap, F. & Haley, W.E. (1995). Mental and physical health of male caregivers of a spouse with Alzheimer disease. *Journal of Aging & Health, 7*(1), 26-31.
- Gallant, M.P. & Connell, C.M. (1998). Stress process among dementia spouse caregivers: Are caregivers at risk for negative health behavior change? *Research on Aging, 20*(3), 267-297.
- Gallicchio, L., Siddiqi, N., Langenberg, P. & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry, 17*, 154-163.
- Glasser, B. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Gonzales, E.W. (1996). Resourcefulness, appraisals, and coping efforts of family caregivers. *Issues in Mental Health, 18*, 209-227.
- Goode, K.T., Haley, W.E., Roth, D.L. & Ford, G.R. (1998). Predicting longitudinal changes in caregiver physical and mental health. A stress process model. *Journal of American Psychological Association, 17*, 190-198.
- Grafström, M., Fratiglioni, L., Sandman, P.O. & Winblad, B. (1992). Health and social consequences for relatives of demented and non-demented elderly: A population-based study. *Journal of Clinical Epidemiology, 45*, 861-870.
- Grafström, M. & Winblad, B. (1995). Family burden in the care of the demented and nondemented elderly – A longitudinal study. *Alzheimer Disease and Associated Disorders, 9*(2), 78-86.
- Grant, J.S., Bartolucci, A.A., Elliot, T.R. & Giger, J.N. (2000). Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury, 14*(12), 1089-1100.
- Grasel, E. (2002). When home care ends – Changes in the physical health of informal caregivers caring for dementia patients: A longitudinal study. *Journal of American Geriatrics Society, 50*(5), 843-849.
- Gubrium, J.F. & Holstein, J.A. (1999). Constructionist perspectives on aging. In V.L. Bengtson & K.W. Schaie (Eds.), (287-305). *Handbook of Theories of Aging* (pp. 287-305). New York, NY: Springer Publishing Company.
- Gubrium, J.F. & Sankar, A. (Eds.).(1994). *Qualitative Methods in Aging Research*. Thousand Oaks, CA: Sage Publications.
- Haug, M.R., Ford, A.B., Stange, K.C., Noelker, L.S. & Gaines, A.D. (1999). Effect of giving care on caregivers' health. *Research on Aging, 21*(4), 515-535.
- Hebert, R., Dubois, M., Wolfson, C., Chambers, L. & Cohen, C. (2001). Factors associated with long-term institutionalization of older people with dementia: Data

- from the Canadian Study of Health and Aging. *Journals of Gerontology, Series A: Medical Sciences*, 56A(11), 693-699.
- Herlitz, C. & Dahlberg, L. (1999). Causes of strain affecting relatives of Swedish oldest elderly; A population-based study. *Scandinavian Journal of Caring Sciences*, 13, 109-115
- Hooker, K., Browman, S.R., Coehlo, D.P., Lim, S.R., Kaye, J., Guariglia, R. et al. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journals of Gerontology, Series B: Psychological Sciences*, 57B(5), 453-460.
- Hubley, A.M., Hemingway, D. & Michalos, A.C. (2003). A comparison of older informal caregivers and non-caregivers living in non-metropolitan areas. *Social Indicators Research*, 61(3), 241-258.
- Huffman, G.B. (2000). Caregiving as a risk factor in mortality. *American Family Physician*, 61(10), 67-69.
- Jeon, Y. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences*, 18, 249-256.
- Keating, N., Fast, J. Dosman, D. & Eales, J. (2000). Services provided by informal and formal caregivers to seniors in residential continuing care. *Canadian Journal on Aging*, 19(1), 23-45.
- Keating, N., Fast, J., Frederick, J., Cranswick, K. & Perrier, C. (1996). Eldercare in Canada: Context, Content and Consequences. *Statistics Canada* 89-570-XPE
- Kelle, U. (2005). "Emergence" vs. "forcing" of empirical data? A crucial problem of "grounded theory" reconsidered. *Forum: Qualitative Social Research*, 6(2). Retrieved October 7, 2005 from <http://www.qualitative-research.net/fqs/>
- Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, J. & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine*, 53, 345-362.
- Kramer, B.J. (2000). Husbands caring for wives with dementia: A longitudinal study of continuity and change. *Health & Social Work*, 25(2), 31-43.
- Levine, C. (2004). Family caregiving: Current challenges for a time-honored practice. *Generations*, 27(4), 5-8.
- Lipkowitz, R. (1992). Alzheimer's disease: The conflict of the caregiver: A grounded theory study. *Dissertation Abstracts International*, 52(11-B), 5760.
- Lorensini, S., & Bates, G.W. (1997). The health, psychological and social consequences of caring for a person with dementia. *Australian Journal on Aging*, 16, 198-202.
- Mason, J. (1996). *Qualitative Researching*. Thousand Oaks, CA: Sage Publications.
- McCurry, S.M. & Teri, L. (1995). Sleep disturbance in elderly caregivers of dementia patients. *Clinical Gerontologist*, 16(2), 51-66.

- McKee, K.J., Phipl, I., Lamura, C. et al. (2002). The COPE index – a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers to older people. *Aging & Mental Health*, 7(1), 39-52.
- Miles, A., Curran, H.V., Pearce, S. & Allan, L. (2005). Managing constraint: the experience of people with chronic pain. *Social Science & Medicine* 61, 431-441.
- Mitrani, V.B., Lewis, J.E., Feaster, D.J., Czaja, S.J., Eisdorfer, C. et al. (2006). The role of family functioning in the stress process of dementia caregivers: A structural family framework. *The Gerontologist*, 46(1), 97-105.
- Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 220-235). Thousand Oaks, CA: Sage Publications.
- Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C., Kuerbis, A.N. & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3), 45-53.
- Navaie-Waliser, M., Springs, A. & Feldman, P.H. (2002). Informal caregiving: differential experiences by gender. *Medical Care*, 40(12), 1249-1259.
- Networks of Centres of Excellence. (2005, August 3). *Making Healthcare a Healthier Place to Work*. Retrieved August 3, 2005 from http://www.nce.gc.ca/media/success/heal99203_e.htm.
- Noelker, L.S. (2001). The backbone of the long-term-care workforce. *Generations*, 25(1), 85-91.
- Occupational Health & Safety Agency for Healthcare in BC. (2005, October 25). *Improving the Health and Safety of Community Health Workers. Final Report*. Retrieved October 25, 2005 from http://control.ohsah.bc.ca/media/final_doc_homesupport_oct7_2005.pdf
- O'Rourke, N. & Tuokko, H. (2000). The psychological and physical costs of caregiving: The Canadian Study of Health and Aging. *Journal of Applied Gerontology*, 19(4), 389-404.
- Orzeck, P., Guberman, N. & Barylak, L. (Eds.).(2001). *Responding creatively to the needs of caregivers*. Montreal: Les Editions Saint-Martin.
- QSR (2005, July 3). *Qualitative research solutions to meet every need*. Retrieved July 3, 2005 from http://qsrinternational.com/products/productoverview/product_overview.htm
- Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods*. Thousand Oaks, CA: Sage Publications.
- Perry, J. (2002). Wives giving care to husbands with Alzheimer's disease: A process of interpretive caring. *Research in Nursing & Health*, 25, 307-316.
- Pinquart, M. & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology: Psychological Sciences*, 61B(1), P33-P45.

- Pinquart, M. & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267.
- Polkinghorne, D.E. (2005). Language and meaning: data collection in qualitative research. *Journal of Counseling Psychology, 52*(2), 137-145.
- Rogan, S. & Lippa, C.F. (2002). Alzheimer's disease and other dementias: A review. *American Journal of Alzheimer's Disease and Other Dementias, 17*(1), 11-16.
- Rubinstein, R.L. (1994). Proposal writing. In J.F. Gubrium & A. Sankar (Eds.), *Qualitative Methods in Aging Research* (pp. 67-81). Thousand Oaks, CA: Sage Publications.
- Ryden, M. (1998). Aggressive behavior in persons with dementia living in the community. *The Alzheimer Disease and Related Disorder International Journal, 2*, 342-355.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health, 18*(2), 179-183.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.
- Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research, 14*(10), 1366-1386.
- Sawatzky, J.E. & Fowler-Kerry, S. (2003). Impact of caregiving: listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing, 10*, 277-286.
- Scharlach, A., & Runkle, C. (1994). Health conditions and service utilization of adults with elder care responsibilities. *Journal of Aging and Health, 6*, 336-352.
- Schofield, H., Bloch, S., Herrman, H., Murphy, B., Nankervis, J. & Singh, B. (Eds.). (1998). *Family caregivers: disability, illness and ageing*. St Leonards, Australia: Allen & Unwin.
- Schultz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*(6), 771-790.
- Schultz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C. & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects study: An ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine, 19*, 110-116.
- Schultz, R., O'Brien, A.T., Czaja, S., Ory, M., Norris, R., Martire et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *Gerontologist, 42*(5), 589-602.
- Schwartz, K.A. (1999). A study of the relationship of caregiving appraisal and depressive symptomatology and home care utilization. *Journal of Community Health Nursing, 16*, 95-108.

- Seale, C. & Silverman, D. (1997). Ensuring rigour in qualitative research. *European Journal of Public Health, 7*, 379-384.
- Segal, M.E. & Schall, R.R. (1996). Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers. *Rehabilitation Psychology, 41*, 303-320.
- Shaw, W.S., Patterson, T.L., Semple, S.J., Ho, S., Irwin, M.R., Hauger, R.L. & Grant, I. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine, 19*, 101-109.
- Silver, H.J. & Wellman, N.S. (2002). Nutrition education may reduce burden in family caregivers of older adults. *Journal of Nutrition Education & Behaviour, 34*(2), 53-58.
- Sörensen, S., Pinquart, M., Habil & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42*(3), 356-372.
- Steffen, A.M., Futterman, A. & Gallagher-Thompson, D. (1998). Depressed caregivers: comparative outcomes of two interventions. *Clinical Gerontologist, 19*(4), 3-15.
- Stein, P.N., Gordon, W.A., Hibbard, M. et al. (1992). An examination of depression in the spouses of stroke patients. *Rehabilitation Psychology, 37*, 121-130.
- Strauss, A. & Corbin, J. (1994). Grounded theory methodology. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 273-285). Thousand Oaks, CA: Sage Publications.
- Strauss, A. & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage Publications.
- Teel, C.S. & Press, A.N. (1999). Fatigue among elders in caregiving and noncaregiving roles. *Western Journal of Nursing Research, 21*, 498-520.
- Vitaliano, P.P., Young, H.M. & Zhang, J. (2004). Is caregiving a risk factor for illness? *Journal of American Psychological Society, 13*(1), 13-16.
- Ward-Griffin, C. (2001). Boundaries and connections between formal and informal caregivers. *Canadian Journal on Aging, 21*(2), 205-216.
- Wells, Y.D. & Kendig, H.L. (1997). Health and well-being of spouse caregivers and the widowed. *Gerontologist, 37*, 666-674.
- Wilcox, S., & King, A.C. (1999). Sleep complaints in older women who are family caregivers. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences, 54*, 189-198.
- Willoughby, J. & Keating, N. (1991). Being in control: The process of caring for a relative with Alzheimer's disease. *Qualitative Health Research, 1*(1), 27-50.
- WorkSafeBC (2004, September 3). *Workers' Compensation Board Statistics 2004*. Retrieved September 3, 2005 from http://www.worksafebc.com/publications/reports/statistics_reports/assets/pdf/stats2004.pdf

- Wright, L.K., Litaker, M., Laraia, M.T. & DeAndrade, S. (2001). Continuum of care for Alzheimer's disease: A nurse education and counseling program. *Issues in Mental Health Nursing*, 22, 231-252.
- Yates, M.E., Tennstedt, S. & Chang, B. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Series B – Psychological Sciences and Social Science*, 54B, P12-P22.
- Zarit, S.H., Reever, K.E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649-655.