

# Seniors Caring for Seniors

Examining the Literature on Injuries and Contributing Factors Affecting the Health and Well-Being of Older Adult Caregivers

Provided to the Public Health Agency of Canada

Prepared on behalf of the Canadian Association of Occupational Therapists, by Janet Jull

January 2010



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Canadian Association of Occupational Therapists  
Association canadienne des ergothérapeutes

## Executive summary

In an effort to prevent injury and support the health and well-being of senior family caregivers, the Division of Aging and Seniors engaged the Canadian Association of Occupational Therapists (CAOT) to undertake an international literature review. The focus of the literature review was upon current understandings of the older adult caregiver in the context of physical impacts of engaging in care-giving.

**Results of this review indicate that the health and well-being of caregivers is an emerging public health issue of paramount concern.** Internationally, caregivers are recognized as providing an important service for people living with illness and disability. As the Canadian population ages, the number of older adults who will require caregiver assistance will increase. Many of the caregivers will be older adults themselves. A growing body of literature suggests that care-giving has a significant impact on the physical health of caregivers. Caregivers currently provide a valuable service to social and health care systems, and make it possible for older adults that need assistance to remain in their community. The service provided by caregivers in Canada, as well as other international communities is anticipated to grow significantly as the population ages.

**Older caregivers are speculated to be at greater risk for injury and subsequent activity limitations and participation restrictions than younger counterparts.** It is speculated that older people are more vulnerable to the negative effects of being caregivers. Research suggests that people, such as older caregivers who experience chronic stress, health impairments and activity limitations, are at higher risk for health problems, in comparison to those that have good health. Although the literature does not establish a causal relationship between care-giving and health, it is recognized that care-giving predisposes participants to impairments, activity limitations and/or participation restrictions through increased risks for: injury or exacerbation of pre-existing issues, risky health behaviours, physiological changes due to chronic stress, changes in sympathetic arousal and cardiovascular state, and participation restrictions in everyday activity. Given these current understandings of care-giving, older adult caregivers would seem to be at additional risk for health problems, and in particular, at risk for physical injury.

**The issues of older caregivers are not well defined in the literature.** While there is a great deal of literature dedicated to the study of care-giving in general, the international literature dedicated to the physical impacts of care-giving, as well as defining the experiences of older caregivers, is limited. The literature also notes the challenge of identifying and understanding the experience of older caregivers, as study has shown that this group will often provide care for years without identification or support. Personal factors, including age, gender, disposition, and ethnicity, have been identified as predisposing caregivers to negative health outcomes. Additionally, the contributing factors of care recipient characteristics such as socioeconomic factors, geography, access to resources and interventions are also identified as having an impact on the health and well-being of caregivers. Care-giving is presented in the literature as having a multi-factorial and multidimensional impact on the caregiver. Research suggests that the issues of older caregivers are far more complex than for other groups, due to the higher risk of caregiver health problems.

**Given the aging population and projected numbers of older members of Canadian society requiring care, the issue of injury prevention for older adults in a caregiver role is an area in critical need of development.** It is a significant oversight to not have a good understanding of who is care-giving and the implications of engaging in care-giving. From the international review of the literature, the following recommendations have been developed by the Canadian Association of Occupational Therapists (CAOT) for the Division of Aging and Seniors, Public Health Agency of Canada:

- **Education of health professionals, such as occupational therapists:** Promotion of best practices is recommended to enable health care professionals to support the caregiver throughout their care-giving.
- **Screening of caregivers for risk of neglect and abuse:** To reduce the risks for neglect and abuse the older adult caregiver should be screened for potentially dangerous or negative care situations.
- **Monitoring of caregivers for changes in health status:** Identifying and monitoring caregivers and their health status will allow potential negative impacts resulting from participation in care-giving, such as caregiver injury to be tracked.

- **Development of supports and health promotion services:** To enable older adult caregivers to provide effective care-giving free of injury, they should be assessed for and have access to appropriate services, such as respite care and caregiver training.
- **Informing caregivers of their rights:** Education of older caregivers of their rights and risks is recommended as part of a health promotion and injury prevention strategy.
- **Recognition of the contributions of caregivers:** Provide caregivers recognition for their invaluable contributions to society to generate the respect, attention and services required to sustain this cohort.
- **Development of best practices and health promotion policy through:**
  - Pan-Canadian approaches to caregiver health and well-being, with coordination among governmental departments, municipal and provincial health authorities, and non-governmental groups.
  - Consulting standards already set such as the International Plan of Action on Ageing and the conventions, recommendations and resolutions of the International Labour Organization, the World Health Organization and other United Nations entities.
  - Consultation with groups such as International Federation on Ageing (IFA), an international non-governmental organization consisting of

NGO, corporate, academic, government, and individual membership.

**While recognized as not being within the mandate of the Division of Aging and Seniors, CAOT also recommends:**

- **Screening of caregivers:** Develop and implement assessment protocols to identify caregiver risk of physical injury, declining health status, financial hardship, neglect, and abuse.
- **Access to service:** Provide access to services such as caregiver training, income support, family and community support and self-help (groups, hotline), social and legal services, and institutional care.
- **Initiation of a collaborative policy response:** Development of a collaborative policy response from governments on care-giving to ensure that social and health systems recognize and support the contributions of caregivers.

**Finally, funding for further study of older caregivers is recommended.** Review of the literature showed that while often identified as an issue, existing research focused specifically on older people within caregiver roles is limited. An important part of such future research is the identification and tracking of older caregivers, and the injuries sustained as a result of their engagement in the caregiver role. In order to develop policies and practices that help support and protect the health of older caregivers, it is critical that intervention studies be performed.

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## Terms

The terms *impairments*, *activity limitations* and *participation restrictions* used in this report were derived from the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization to define the ways in which people experience function, disability and health in the context of their environment. (WHO, 2003). The ICF provides a multi-dimensional perspective from which to understand the health impacts of care giving.

*Senior or Older Adults*: are defined as persons over the age of 65. \* **Note**- we recognize some of the injury prevention and care-giving literature may not target seniors in particular but, where possible, the focus is on seniors caring for seniors (age 65+) (Public Health, Division of Aging and Seniors, September 2009, written communication).

*Care-giving tasks* and responsibilities can vary. Some caregivers provide help with instrumental activities of daily living (IADLs) where the caregiver helps with chores, cooking, shopping, housework and yard work. When care-giving demands increase, caregivers must often assist with activities of daily living (ADLs) such as:

- personal care, including bathing, dressing, toileting and grooming;
- helping with medications, including providing medications and needles to the ill individual: and
- other health care including the use of highly technical equipment.

## Introduction

Caregivers provide an important service for the health and well-being of older adults living in Canada. As the Canadian population ages, the number of adults over the age of 65 is increasing. With the increasingly older adult population in Canada, there will be more and more older people caring for one another. These groups of older caregivers may be more vulnerable in the care-giving situation, due to health issues (Canadian Study on Health and Aging, 1994b). As a result, these older caregivers may be more susceptible to the negative effects of caregiving than their younger counterparts. Caregivers take on responsibilities that are intense and often long lasting; many caregivers

Some caregivers also undertake the management of care. This includes finding out about, arranging for and ensuring the delivery of formal and informal services (advocacy and management of care) as well as social and emotional support. While caregivers can assume a mixture of tasks and there may be more than one family caregiver involved, often there is a primary or main caregiver, who has most of the responsibility for the care of the individual (Public Health, Division of Aging and Seniors, September 2009, written communication).

A *caregiver* (often termed informal/family caregiver) is an individual who provides ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive or mental health conditions (Canadian Association for Community Living, 2003).

*Occupational therapy* is the art and science of enabling engagement in everyday living through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life (Townsend & Polatajko, 2007).

*Occupations* are groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves, including looking after themselves, enjoying life, and contributing to the social and economic fabric of their community (Townsend & Polatajko, 2007).

of older adults with dementia report being on duty 24/7 (Bedard et al, 2005). Even for those caregivers not providing around the clock care, the vast majority, especially in cases of dementia, will experience increases in the amount of care they provide over time (Taylor, Jr., Kuchibhatla, & Ostbye, 2008). These responsibilities are frequently unpredictable and uncontrollable, leading to considerable restrictions in daily activities of the caregivers (Kosberg & Cairl, 1986). Further difficulties arise from lack of information and training to undertake the role of a caregiver (Baumgarten et al., 1992). Evidence shows that most caregivers are ill-prepared for their role and provide care with little or no support (Family Caregiver Alliance website) and as a result are at risk for injury

(Brown & Mulley, 1997). Preventing injury and promoting health of older caregivers will reduce potential health care and social costs (Baumgarten, 1989; Jutras & Lavoie, 1995).

A recent Canadian survey of primary and secondary caregivers revealed that the majority (63%) experienced physical changes directly related to their caregiving duties. A table showing the specific changes reported is presented below (Harris/Decima, 2008).

Physical change	Percent
Fatigue	47
Difficulty sleeping	36
Headache	23
Back pain	21
Weight gain	19
Worsening of health condition(s)	15
Increased frequency of colds/flu	9
Weight loss	9

Source: Table quoted in *The Health Impact of Seniors Caring for Seniors- Review* prepared for the Public Health Agency of Canada, Michel Bédard, PhD, Canada Research Chair in Aging, Public Health Program, Lakehead University. March 2009.

There is a continued reliance by society on caregivers, with anticipated increases in the need for caregivers within the older adult population. Supporting the well-being of older adult caregivers is essential, for society and for people that are growing older in Canada. Caregiver support, including injury prevention schemes will enable older adults to safely sustain participation in the occupation of caregiving and provide opportunities for older adults requiring care to stay in their homes/ minimize institutionalization. Strategies aimed at promoting health and well-being for older caregiving adults creates a more just society for those supporting the most vulnerable members of our society. However, despite the international focus on care-giving research, little attention has been given to the public health outcomes for caregivers (Talley & Crews, 2006).

In an effort to prevent injury and support the health and well being of caregivers who are seniors, the Public Health Agency of Canada's Division of Aging and Seniors sought the expertise of the Canadian Association of Occupational Therapists (CAOT). CAOT is the national professional association of occupational therapists that represents over

12, 000 occupational therapists in Canada. CAOT is a non-profit organization that provides advocacy, resources and member services to promote excellence in occupational therapy. As a professional group, occupational therapists are concerned with promoting health, well-being and justice through occupation, in the workplace and at home.

Occupational therapists are experts in enabling occupations using evidence based processes that help clients do what they need to do and what they want to do in their daily lives. Occupational therapists define an occupation as much more than a chosen career. Occupation refers to everything that people do during the course of everyday life. Each of us has many occupations that are essential to our health and well-being. Occupational therapists believe that occupations describe who you are and how you feel about yourself. Care giving is an important occupation to an increasing number of adults in Canada.

The occupational therapy focus on person, environment and occupation is complimentary to an injury prevention approach for older adult caregivers. Occupational therapists understand that people successfully engage in occupations of life when the demands of the occupation fit within the capacity of the person and are supported by the environment. Occupational therapists understand that the environment that can support or hinder a person's ability to engage in occupations and the environment is a broad term that consists of cultural, institutional, physical (built) and social components.

This international literature review focuses on the following questions:

1. What does international research tell us about older adult caregivers and the impairments, activity limitations, and/or participation restrictions caregivers may experience as a result of caregiving?
2. What impairments, activity limitations, and/or participation restrictions do older adult caregivers most commonly experience?
3. Within the older adult caregiver demographic, who is most vulnerable or most at risk for these impairments, activity limitations and/or participation restrictions?

## Method

### Search strategy

The following electronic databases from 1980-2009 were searched: Medline (medical literature), Embase (European medical lit), CINAHL (nursing and allied health) and AARP-Ageline (interdisciplinary literature on gerontology and aging). A boolean search was conducted using the terms, or variations of the terms: “aged” and “older” and “caregiver” and “adults” or “home health nursing” and “quality of life” or “health status” or “health status indicators” or “health behavior” or “health promotion” or “attitude to health. In addition, reference lists of relevant literature were referred to as additional sources for articles.

Reports and conference proceedings were sourced via Internet searches, contact with workers in the field, and on-site library searches of journals and books. Exclusion criteria were not limited by year, publication type, population or language. Applied limits were by age (65+) only, with analysis of each article for consistency with the study question.

### Background

Demographic trends in Canada indicate that the proportion of people over the age of 65 is rapidly increasing due to factors such as: the large number of people born in the post World War II era (1940-1960); increases in life expectancy; and prolonged survival rates for people with disabilities. The increasing proportion of seniors in the population is creating demographic changes to which the Canadian health care system needs to adapt. Canada is not unique in anticipating the need to meet these demographic challenges. The Organization for Economic Cooperation and Development (OECD) has identified the issue of health and well-being of older adults as an issue of concern (Oxley, 2009). The aim of the OECD is to provide opportunities for member states to compare policy experiences, seek answers to common problems, identify best practices and coordinate domestic and international policies. The OECD places priority on both healthy aging and lowering associated health care costs.

Caregivers are already identified as key players in the strategy to meet the needs of older adults. In findings from their 2002 General Social Survey and 2001 Canadian Community Health survey, Keefe and

Legare (2008) have used data to make projections for future demand in Canadian human resources for elder homecare up to 2031. According to these estimates, demand for homecare is anticipated to grow in every age group, with informal care remaining the most important contributor of support to Canadians living with a disability.

The importance and value of caregivers is recognized internationally. For instance, in Australia it is estimated that there are 2.6 million caregivers providing support to older persons with a disability, saving the government 30.5 billion a year (Carers Victoria, 2007). Current estimates for replacement costs for unpaid care-giving in Canada indicates a significant economic contribution by caregivers; estimates for care provided in 2009 range between 25 to 26 billion dollars (Hollander, Liu & Chappell, 2009).

A growing body of literature suggests that care-giving has a significant impact on the physical health of caregivers. When compared with non-caregivers, caregivers have been found to report poorer levels of perceived health, a greater number of physical symptoms, and more chronic illness (Patterson & Grant, 2003). This is becoming an area of focus globally because of the aging populations. In the future, it is anticipated that more people that are older will be cared for by informal caregivers, who are themselves older (Rosenman, LeBrocq & Carr, 1994). In fact, it has been estimated that one in six of all adults are informal caregivers, and that 13% of people over the age of 65 currently provide some form of care to others (Rowlands, 1998). The issue of how well researchers and social services understand the needs of older caregivers has been raised as an area of concern (Wenger, 1990).

The literature on older caregivers is limited. However, it is speculated that older people are more vulnerable to the negative effects of being caregivers through increased vulnerability to care-giving stressors, and that these caregivers may often be providing care while simultaneously dealing with their own health issues (Kim & Keshian, 1994). Older caregivers and those caring for an ailing spouse are also found to provide more care in all daily tasks (Wenger, 1990). These older caregivers will be increasingly relied upon in the future, yet they must also safeguard their own health to be able to continue to care for themselves. While older caregivers share some of the same characteristics of other caregivers with physical or affective health

impacts (O'Rourke & Tuoko, 2000), the issues associated with care-giving at advanced ages are not clearly defined. Therefore, it is critical that an understanding of how care-giving impacts the health of older caregivers be determined if health and social policy is to be developed with the objective of best supporting older care providers.

The intent of this literature review is to provide a foundation upon which to understand the impact of care-giving on older caregivers. The primary question guiding this literature review is: "What does the international literature tell us about older caregivers, and what impairments and activity limitations and/or participation restrictions may they experience as a result of care giving?"

A review of the international care-giving literature was conducted to address this question, with the purpose of defining the issues and contributing factors that affect the health and well being of older informal caregivers, thereby pre-disposing them to physical injury. While there is a large body of literature exploring the experiences of caregivers in general, it was found that sources specifically addressing the experiences of older caregivers were far more limited. As a result, literature in this review includes that of studies of care-giving adults of all ages, and that of older caregivers, defined as 65 years and older, when possible.

Understandings of the health impact of care-giving are not yet well defined. The literature presents care-giving as having both a multi-factorial and multidimensional impact on the caregiver (Shaw et al, 1997). Informal care-giving relationships are often defined as vulnerable because of the many factors influencing the caregiver. Therefore, to understand the implications of care-giving on caregiver health and accompanying risks of physical injury, one must first understand the many factors that influence the caregiver. As the literature shows, these factors include a multitude of interactions between the individual caregiver characteristics with those of both the care receiver and the care environment. Although not well defined, some research suggests that the issues of older caregivers are far more complex than those for other groups, due to the higher risk of caregiver health problems (McGarry & Arthur, 2000).

## What impairments and activity limitations and/or participation restrictions do older adult caregivers most commonly experience?

In reviewing the literature it was evident that there are both physical and psychosocial impacts of engaging in care-giving. First, the literature documenting the physical and the psychosocial impacts of care-giving on caregiver health which result in caregiver impairments and activity limitations will be presented. Next, a review of the literature exploring the impact of care-giving on a caregiver's ability to participate in life's activities will be discussed, and finally, the difficulty in providing perspective on the impact of care-giving (reflective of all care providers) will be presented.

## Physical impacts of care-giving and resultant impairments and activity limitations

In review of the literature, few studies were found to focus solely on the physical impact of care-giving, despite strong indicators that physical injury of caregivers should be an area of concern. A national survey of Australian caregivers cited that one third of respondent caregivers reported the experience of a physical injury as a result of their care-giving activity. This same study reported that one half of caregiver respondents reported a decline in their physical health as a result of care-giving (Carer Association of Australia, 1999). Another study employing interviews and descriptive measures proposed to address the limited knowledge of the competence and safety of caregivers who were lifting and handling care recipients. This study interviewed 41 caregivers, ranging in age from 29 to 85 years. The study concluded that caregivers of elderly disabled people experience difficulty with the physical demands of care-giving, and that many caregivers themselves are in poor physical health. In addition, the study reported that caregivers engaged themselves in some high-risk health behaviours such as lifting without supervision or training. The study concluded that caregivers were at risk of injury, particularly back injury (Brown & Mulley, 1997).

The risk of injury during lifting tasks in care-giving is only one of many potential physical impacts. Despite the range in caregiver characteristics and influencing factors evident in the review of the literature, many of the studies reported poor health outcomes for caregivers, including symptoms of depression, poor self-reported health, and less positive health behaviours. This was shown in studies such as a survey conducted in California, which included 628 caregiver respondents, and 6,599 non care-giver respondents (Scharlack, Runkle, Midanik & Soghikian, 1994). The findings indicated that caregivers were more likely to report backaches, insomnia, arthritis, rectal problems, and hearing problems. It also found that these caregivers were more likely to report having two or more concurrent health conditions of any kind (Scharlack et al, 1994). Caregivers were found to experience negative health consequences in other studies. This was especially true in on-going care-giving, or when transitioning to heavy physical and emotional care-giving, such as in the case of caring for people with dementias (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003). Such studies suggest that while physical injuries of caregivers are not well documented in the literature, risk of physical injury may be one outcome of participation in care-giving.

Relatively few articles were found that define the specific physical impact of care-giving. Instead, the literature to explores the impact of care-giving in a more general way, comparing the physical and psychosocial impacts of care-giving experiences between caregivers and non-caregivers. In many of these studies, the impairments and activity limitations of care-giving are presented as the result of inseparable physical and psychosocial effects of care-giving.

Additionally, these comparative studies do not draw similar conclusions on the impact of care-giving. Some studies conclude that caregivers have negative health outcomes as a result of care-giving, whereas others indicate that there are strong similarities between caregiver and non-caregiver health. For instance, in a study comparing the physical and psychosocial impact of caring for a person with dementia in comparison to people who were not acting in a caregiver role, it was concluded that caregivers experienced more global self-reported health issues than non-caregivers. In addition, comparisons within the caregiver group indicated greater negative consequences for full-time caregivers than for those

who were able to act as caregivers in a part-time capacity (Lorenzini & Bates, 1997).

However, another study compared older spousal caregivers to non-caregivers, and findings suggested that both groups were equally likely to experience an extended illness or disability, have an unhealthy medical rating from a nurse or be hospitalized. The study also indicated that the caregiver group was at a significantly higher risk for serious illness. In addition, comparisons within the caregiver group showed that ill health was more common when providing more physical assistance (Shaw et al, 1997). This finding contradicts much of the literature that establishes care-receiver behavioural issues as the greatest predictor of poor caregiver health (Pinquart & Sorenson, 2003). Finally, in study of older Canadian caregivers, it was found that caregivers and non-caregivers were not significantly different in terms of quality of life, self-reported health, and most aspects of social support and age identity. In fact, respondents in both groups reported positive levels of quality of life and health status (Hubley, Hemingway & Michalos, 2003).

The contradictions reported in the literature when the impact of care-giving is contrasted between caregivers and non-caregivers may be attributable to a number of factors, including:

- the ways in which the studies were conducted, inconsistent definitions of the term “caregiver” (Schulz, Newsom, Mittelmark, Burton, Hirsch & Jackson, 1997); and
- the possible strong positive (Kramer, 1997) or negative (Cattanach & Tebes, 1991) effects of care-giving with certain groups, as it is possible that differentiation of certain care receiver groups were not done (eg. caregivers caring for people diagnosed with dementias in the caregiver samples were not identified). Additionally, senior spouses have been found to inconsistently identify with the term “caregiver”, viewing their role in care-giving as an extension of what their role is as a spouse.

A meta-analysis of studies comparing psychological and physical health found that the differences between caregivers and non-caregivers on measures of stress, depression, levels of subjective well-being and physical health were small to medium. Nevertheless, caregivers did rate lower in each of these areas. The greatest differences between caregivers and

non-caregivers – with caregivers scoring as most affected – were in the areas of depression, stress, and self-efficacy (Pinquart & Sorenson, 2003).

While many articles made reference to the limited amount of study focused on defining the physical impact of care giving (Pinquart & Sorenson, 2007), it was most common to find the multi-factorial issues influencing health associated with care giving explored. Such information explains how caregivers are affected by care-giving, and how participation in this occupation may make them more vulnerable to negative health outcomes, such as physical injury.

## Multi-factorial issues influencing caregiver impairment

The range of factors covered in the literature was large, and the diversity of the findings made it challenging to draw general conclusions and understand the predictors of poor health.

For example, in a study looking at perceived health and functional status among spousal caregivers of frail older persons, it was concluded that caregiver emotional strain was the strongest common predictor of both poor perceived health and functional limitation (Mui, 1995). Another study conducted with older caregivers found that the number of physical symptoms were strong predictors of stable depression (Zunsunegui, LlacerCentro & Beland, 2002). Finally, in a study looking at health predictors for middle-age to older family caregivers, caregiver physical health was found to be predicted by: caregivers' baseline self-reported physical health; the impact of care-giving on their social and leisure time activity; and their relationship with their care recipient (Meddaugh, O'Bryant & Straw, 1991). Caregiver health has been related to: perceptions of stress, or care-giver reports of poor coping with care-giving, surrounding the provision of activities of daily living assistance; the frequency of behavioural problems; association with spouses diagnosed with dementias and associated dysfunctional behaviours; and caregiver satisfaction with their leisure activities (Shanks-Elroy & Strobino, 2001). Studies such as these illustrate the variability found in the literature when describing predictors of poor physical health.

Two meta-analyses were located, both of which explored factors correlating with physical health. The first study, done by Pinquart and Sorenson (2003)

reviewed 176 studies. From this study, a general profile of caregivers was developed. The average caregiver age was 60.6 years with average length of care provision of 54 months, for an average of 55 hours a week. In this study, predictors of physical health were not identical to those of psychological health, although there was found to be a relationship between physical and psychological health. This finding corresponded with the results of other studies, which also confirmed that predictors of physical and psychological health are not similar (Pinquart & Sorenson, 2007) although they are related to each other.

Caregiver depressive symptoms were strongly associated with physical health in the research literature. Higher levels of care-recipient behaviour problems were more consistently related to poorer health. The effects of care-giving stressors were found to be most significant with older people, caregivers to people with dementia, and men (Pinquart & Sorenson, 2003).

In another meta-analysis proposing to “examine and critique the literature on self-reported health and physiological functioning in caregivers of people with dementia” (Vitaliano, Scanlan & Zhang, 2003, p.946) 23 studies met the criteria for inclusion. When examining comparisons of health between caregivers and non-caregivers, it was found that caregivers were at a slightly higher risk for health problems. In addition, the meta-analysis found strong relationships within physical health to stress hormones, antibodies, and caregiver global reported health. These relationships connected the issues of psychosocial health with the potential for physical impairments and activity limitations (Vitaliano, Scanlan & Zhang, 2003).

A meta-analysis can provide general trends in caregiver health. In this literature search, these meta-analysis studies were the only ones to specifically address caregiver physical health. This is attributable to the variability in studies that examine a broad range of factors influencing caregiver health. While such coverage of the topic is illustrative of the complex and individual nature of care-giving issues, it also decreases the possibility of drawing strong conclusions based on larger comparisons between subgroups in a synthesis of the literature. The literature shows that caregivers do not function as homogenous groups acting within similar circumstances.

An understanding of the potential for impairments and activity limitations, and the potential for associated physical injury that are secondary to care-giving requires an understanding of the literature exploring the psychosocial impacts of care giving and the relationships between physical and psychosocial health.

## The role of psychosocial impacts of care-giving with caregiver health

The literature documents the profound impact of care-giving on the psychosocial health of caregivers. There are many different situations in which caregivers are needed, although it is widely accepted that caring for someone who is suffering dementia is the most difficult situation (Ritchie & Lovestone, 2002). Diseases with associated dementias are defined by the literature to be most care intensive (Pinquart & Sorenson, 2003). In these situations, caregivers must typically provide care for between 3 to 15 years, while the disease runs its course (Mölsä, Marttila & Rinne, 1986). The most common of these diseases is Alzheimer's disease.

Today, 75% of people diagnosed with Alzheimer's dementia are older than 65 years of age (Ganguli, Dodge, Chen, Belle & De Kosky, 2000). In 2009 it was estimated that the world population with Alzheimers was 35 million, however this figure is expected to grow to 107 million by 2050 (Brookmeyer, Johnson, Ziegler-Graham, Arrighi, 2007). In the United States, an enormous public health impact is anticipated, with the number of people expected to develop Alzheimer's disease projected to quadruple in the next 50 years (Brookmeyer, Gray & Kawas, 1998). The pressures associated with such a population demographic change are also of concern to many other countries.

Other increasingly significant populations affected by dementia include people who have had a stroke or who suffer from Parkinson's disease. These populations may experience significant cognitive and behavioural changes with which caregivers must cope. These problems are also known to more commonly affect older people (Lyons, Stewart, Archbold, Carter & Perrin, 2004; Liberman & Fischer, 1995).

In research with caregivers to people with health issues other than dementia, it was found that

caregivers also experienced a significant psychological impact as a result of their care duties. In a study of caregivers to people with heart failure, it was found that caregivers were vulnerable and experienced significant life changes, including changes to their daily routines for meeting the demands of care, and experiences of anxiety (Luttik, Blaauwbroek, Dijiker & Jaarsma, 2007). Additionally, it was noted that these diseases can require prolonged periods of care-giving.

Given an aging population, there are increasing numbers of people that will live for many years with other chronic illnesses, such as cardiopulmonary disease. For instance, a Canadian study looked at experiences of older wives who were caring for husbands with chronic obstructive pulmonary disease (COPD) – a progressive and degenerative process, the prevalence of which is rapidly increasing. Good care can extend the life of someone diagnosed with COPD by up to 15 years; however, this is only possible with on-going care that is typically provided by both spousal caregivers and health care professionals. The study concluded that more men than women are diagnosed with COPD, which will cause many older women to cope with the responsibility of caring for their spouse (Hussey, 2000).

Studies such as this illustrate the unique and challenging situations within which the older caregiver must function.

## Caregiver burden

While care giving is complex, it is also defined as stressful – both physically and psychologically. As dementia progresses with further deterioration of care recipient health, caregivers must not only provide physical care, but also undertake care-giving duties throughout the physical and mental deterioration of the care-recipient. This results in chronic exposure to stress (Stephens, Kinney & Ogrocki, 1991).

The term “burden” is typically used in the literature to describe the complexity of the caregiver experience. The term refers to the negative effects of care-giving on physical, psychological, emotional, social and financial well-being of the caregiver (George & Gwyther, 1986). Burden is influenced by many factors. For instance, one published study documents that the duration of caregiving influences the amount of burden perceived by participants, with those care-

giving for longer periods of time expressing greater burden (Gaynor, 1988).

Burden is used as an indicator of caregiver health. There is evidence of a correlation between the caregiver's experiences of burden with the well-being of the caregiver. Andren and Elmstahl (2008) found that burden was a predictor of perceived health. Caregivers who reported lower burden also reported better health while those who indicated higher burden reported poorer health. In looking at predictors of burden for spousal caregivers of care-recipients with dementia, Vitaliano, Russo & Young (1991) concluded that caregiver reports of burden correlated to adverse effects on the physical health of caregivers. Burden was also shown to be a predictor of emotional distress (Brodaty & Hadzi-Pavlovic, 1990; Brodaty, Gresham & Luscombe, 1997).

Research associates perceived burden with individual health habits. Some findings suggested that those perceiving lower subjective burden practice more health-promoting behaviours than those with higher subjective burden (Sisk, 2000). This particular study describes the health behaviours of a sample of older adult spousal caregivers (amount of alcohol consumption, exercise, sleep patterns, smoking, and weight maintenance) and investigated predictors of decreased self-care after care-giving began (Sisk, 2000). In a similar study, it was found that caregivers who reported experiencing more burdens also reported a greater number of depressive symptoms, provided a higher number of activities of daily living tasks to care-recipients, and spent more hours each day providing care. These individuals also had lower rates of successful self and spousal care, and were found to be at higher risk for negative health behaviours, in comparison to those reporting a lower perception of burden (Gallant & Connell, 1997).

In summary, the literature presents the care-giving experience as one of constant exposure to some degree of chronic and psychosocial stress (Vitaliano, Scanlan & Zhang, 2003). Exposure to chronic stress could predispose caregivers to greater risk of physical injury, such as back problems or exacerbation of pre-existing conditions such as arthritis.

## Chronic stress

Chronic stress exposure has been documented as a factor which predisposes caregivers to both illness and

risky health behaviours. There are two ways in which the chronic stress of care-giving impairs the health and well-being of caregivers. The literature documents the influence of chronic stress on hormones, which in turn influence physiologic responses. This area of study documents the effects on people exposed to chronic stress, citing their poor immune response, slower wound healing, significantly higher levels of plasma insulin (Patterson & Grant, 2003), and changes in sympathetic arousal and cardiovascular state (Jorgenson, Johnson, Kolodziej & Schreer, 1996; Moritz, Kasl & Ostfeld, 1992). These responses predispose them to illness and disability.

A meta-analysis of 23 studies comparing the health indicators of caregivers for people with dementia with non-caregivers matched for age and gender found that stress hormones in caregivers were 23% higher, and that their antibody responses were 15% lower than those of non-caregivers. These findings suggest that care-giving may influence the physical health of caregivers (Vitaliano, Scanlan & Zhang, 2003).

The other way in which chronic stress influences the health of caregivers is through risky health behaviours (Vitaliano, Scanlan & Zhang, 2003). Such findings may provide the key to understanding many of symptoms described by caregivers, such as depression and sleep problems (Bedard, 2009).

The limitations of caregiver participation in daily activity are poorly documented. Also poorly documented are the underlying reasons for such limitations, such as caregiver injury, that affect caregiver participation in daily activity. Community support services, such as occupational and physical therapy, when available, are most commonly directed at the disabled or ill person, rather than the caregiver. Caregivers must seek medical attention through their family practitioner.

## Activity limitations and participation restrictions in adult caregivers

Caring for a person with an illness or a disability can negatively impact daily life activity. As shown in this literature review, the demands of care-giving are often evident in the high incidence of stress and depression experienced by caregivers, as well as by the significant impact on their physical health. Additionally, the performance of activity, or the ability to participate

in daily life routines, may be negatively influenced by the care-giving role (Williamson, Schaffer & Schulz, 1998). Understanding the impact of restrictions on the ability to participate in daily tasks is important, as some research indicates that restriction of activity due to stress is associated with depression (Williamson et al, 1998; Williamson, 1998; Williamson & Schulz, 1992).

Fulfilling the role of a caregiver has a significant impact on the participation of individuals in daily life activity. In a study comparing non-caregivers to caregivers, caregivers were found to spend more time on domestic and volunteer work. This study showed that life activities are influenced by the care-giving role (Michelson & Tepperman, 2003). Participating in care-giving also impacts on leisure activities of the caregiver, which are activities engaged in for social reasons (White – Means & Chang, 1994; Dunn & Strain, 2001). Instrumental activities are described as those that must be performed for daily maintenance, such as the care of self and others. Loucks-Atkinson, Douglas, Kleiber, and Williamson (2006) proposed exploring a gap in the literature, and determined how participation restrictions influenced indicators of caregiver well-being. For the study, well-being was defined as multi-dimensional, consisting of social support, depression, physical symptoms, and subjective health status. Both expressive and instrumental activity was evaluated. The findings indicated that activity restriction in both activity areas predicted depression and physical symptoms. These findings correlated with other studies that found greater restrictions in daily activity were associated with more chronic health issues (Williamson & Schulz, 1992). The findings that limited participation in expressive activity predicted poor short-term health outcomes is congruent with other research that found a correlation between loss of leisure activities and symptoms of depression (Katz & Yelin, 2001). However, it was also found that limited participation in instrumental tasks, was predictive of even greater negative health impacts for the caregiver (Loucks-Atkinson et al, 2006). In addition, Law, Steinweinder & Leclair, (1998) suggest links between disengagement from self selected occupations and negative psychological outcomes for the individual.

Care-giving impacts participation in activity, and may result in both physical and psychological withdrawal from meaningful daily occupations. It is possible

that withdrawal from daily occupations of living may affect the predisposition for sustaining an illness or injury while care-giving. The social isolation that may result from care-giving is well documented, with some studies indicating that 1 in 5 caregivers reported making changes in social and holiday plans as a result of care-giving involvement (Fast, 2009).

## Limitations of the literature

Many studies acknowledged, as a research limitation, the potential of bias to include distressed caregivers over those caregivers that function in the role without negative consequences (Schulz, Visintainer & Williamson, 1990; Broe et al, 1999). In addition, the literature notes the challenge of identifying caregivers before caregivers are in distress; often, caregivers provide care for years without support of any kind. Researchers in one study documented that caregivers were providing care for an average of five years before the care-receiver was diagnosed with dementia (Molloy, Lever, Bedard, Guyatt, & Butt, 1996). These unidentified caregivers are sometimes described in the literature as “hidden patients.” A detailed family and social history of older patients by their health care providers is recommended, so that caregivers can be identified and early intervention can be offered to prevent a health crisis (Novielli & Parks, 2001; Arber & Ginn, 1990). Additionally, when compared with other age groups, older caregivers have been identified as less likely to ask for assistance with care-giving tasks and may be more difficult to identify as a result (Wenger, 1990).

During the scan of the international literature, most articles were found to address the negative impacts of care-giving. However, a small body of research suggesting some positive outcomes for care-giving were also located. A study undertaken in Finland as part of a major international project on the coping strategies of caregivers found sources of satisfaction among relatives who were caring for older family members. The most common finding was that caregivers reported the experiences of feeling wanted and needed as positive outcomes (Kuuppelomaki, Sasaki, Yamada, Asakawa & Shimanouchi, 2004). This finding is common when positive aspects of care-giving are explored (Russell, 2002). In a Swedish study of loneliness as a predictor of quality of life among older caregivers age 75 and older, 4,278 people were surveyed. It was found that caregivers had a larger social network than non-caregivers, and reported feelings of loneliness

less often than non-caregivers. There were gender differences, with frequency of loneliness being higher among women. Loneliness and a small or non-existent network were significantly associated with low quality of life among caregivers and non caregivers (Ekwall, Sivberg & Hallberg, 2005).

In another study that explored the effects of engaging in multiple roles, it was found that older caregivers who engaged in work and/or volunteer work reported better health. This study also found that caregivers who engaged in higher informal social activity also reported the lowest functional limitations (Rozario, Morrow-Howell & Hinterlong, 2004).

It should be noted that reviews of literature reveal that positive aspects of care giving and related concepts have been included in many studies, but the definitions of positive care-giving and measurement of positive factors vary (Cohen et al, 1994).

These findings suggest that while the literature generally links care-giving with the potential for negative health impacts, there may also be some benefits to the caregiver in the caring relationship. Better understandings, such as details on the nature of the care provided, will develop a richer knowledge of the caregiver role, and thereby enable support that builds on the benefits of this unique relationship.

### Impairments, activity limitations and participation restrictions commonly experienced by older adult caregivers

Although the literature does not establish a causal relationship between care-giving and health, it is recognized that care-giving predisposes its participants to impairments and activity limitations and/or participation restrictions through increased risks for:

- Effects of physical exertion – for injury or exacerbation of pre-existing issues (i.e. arthritic condition);
- Risky health behaviours such as neglecting health promoting physical activity, or not attending regular physical check-ups;
- Physiological changes due to chronic stress, such as increased risk of infection;
- Changes in sympathetic arousal and cardiovascular state, and

- Participation restrictions in everyday activity, due to care-giving tasks.

When care-givers provide care over long periods of time, or to persons with dementia, these effects may be exacerbated. In addition, the general research suggests that those experiencing chronic stress and health impairments and activity limitations are at higher risk for health problems in comparison to those that have good health and no chronic stress. For this reason, poor identification of caregivers possessing impairments and activity limitations prior to participating in care-giving activity is a significant oversight. Given current understandings of care-giving, older adults would seem to be at additional risk for health problems, and in particular, at risk for physical injury.

Finally, the literature on activity and care-giving suggests that participation in care-giving may significantly limit the caregiver in their performance of daily tasks. Literature on the importance of occupational engagement links increases in dependency and depression with withdrawal from daily tasks (Law, Steinweinder & Leclair, 1998), thereby suggesting that care-giving can also predispose caregivers to poor health, and also lead to the risk of injury, such as musculoskeletal injury or exacerbation of pre-existing conditions.

### Within the older caregiver demographic, who is most vulnerable or most at risk for these impairments and activity limitations and/or participation restrictions?

Research in care-giving strives to define relationships between the variables that influence the health of caregivers. There are many articles that subjectively and objectively explore health and psychosocial factors within the caregiver demographic. However, due to the large range of variables, a lack of studies that evaluate specific caregiver subgroups, as well as a diverse range of approaches to study methodology, it is difficult to draw definitive conclusions on who is at greatest risk of impairments, activity limitations and participation restrictions resulting from the caregiver role.

Understanding the factors which may predispose caregivers to negative health outcomes could aid in identifying those caregivers who may be at risk for

physical injury and illness, as well as allow the development of specific medical and psychosocial interventions. For this literature review – with the exception of some limited meta-analyses – the studies were found to cover a range of topics that generally focused on defining caregivers with certain characteristics as being more or less vulnerable to the negative impact of care giving.

## Vulnerability and care giving

The care giving literature defines vulnerability as a characteristic that cannot be modified by the individual (Mechanic, 1967) and include age, gender, disposition, and ethnicity (Lazarus & Folkman, 1984) (Robins, 1978) (Zubin & Spring, 1977). Vulnerabilities are factors that are present prior to engaging in care giving (Vitaliano et al, 2003), although they may not be defined as a vulnerability until participation in care giving. There was a broad range of information in the literature on the evaluation of caregiver experiences. Much of this information focused upon caregivers in general, rather than on specific caregiver subgroups, such as older caregivers.

## Age

The literature generally attributes negative health consequences to care-giving at an advanced age. However, these studies do not clearly indicate the effects of age upon participation in the care-giving role. For instance, in some literature it is reported that older caregivers experience greater negative health outcomes as a result of care-giving, but this is reported in a variety of ways. One study identified vulnerable caregivers as being more likely to belong to the following demographic: 65 years of age or older, married, and having poor health or a serious health condition (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis & Donelan, 2002). In another study of age and care-giving, it was concluded that even without pre-existing health conditions, being older was the most likely predictor for poorer self-assessed health and functional performance, and psychosocial issues (Lu, 2001). In yet another study, findings indicated that being older was related to experiencing greater health problems as a caregiver; if health problems were already experienced, then care-giving was found to exacerbate these issues (de Frias, Tuokko & Rosenberg, 2005). Unfortunately, in these studies, physical injuries as a result of care-giving are not documented.

There is also a body of literature that refutes the correlation of caregiver age with poor health outcomes. In a Canadian study comparing older caregivers with non-caregivers, it was found that older caregivers and non-caregivers were not significantly different in terms of quality of life, self-reported health, and most aspects of social support and age identity. Instead, respondents in both groups reported positive levels of quality of life and health status (Hubley, Hemingway & Michalos, 2003). Care-giving creates both unique opportunities and issues for older people. A small body of literature on care giving in older age purports that positive outcomes may arise for individuals who choose to participate as a caregiver (Rozario, Morrow-Howell & Hinterlong, 2004).

Some studies indicate that there may be unique differences between the approaches of older and younger caregivers. In a qualitative study inclusive of caregivers 75 years and older, it was concluded that the higher risk of health issues amongst this older cohort produced more complex care-giving issues. However, it was also found that the caregivers tended to downplay their care-giving situation in an effort to make it more manageable, and consequently were reluctant to access formal services for assistance (McGarry & Arthur, 2000). In addition, there is also the fear of having to place the family member in a long-term care facility, a consequence often perceived as negative by a spouse of an ill or disabled person (Personal communication, S. MacLeod, November 13, 2009).

These findings support other studies that compared older and younger caregivers, in which it was found that the younger cohort identified informational support and training as an important part of their social support while older caregivers did not. Younger caregivers were also more likely to complain or criticize the health care system and healthcare workers. A common theme amongst older caregivers was to focus on the importance of keeping a positive outlook through out the care-giving experience (Smith, Gignac, Richardson & Camerson, 2008). Such findings, reflecting an attitude towards care-giving that is unique to older caregivers, have been replicated in other studies (Navon & Weinblatt, 1996). These studies infer that it may be difficult to identify older caregivers or to obtain accurate information from them, given the inclination of older caregivers to downplay their role.

One relevant meta-analysis was located which provided information on the relationships between age and care-giving. Data was synthesized on the correlates of physical health of caregivers. Greater care-giving demands, such as care-giving for a person with dementia, resulted in greater negative physical outcomes for older caregivers than it did for younger caregivers (Pinquart & Sorenson, 2007). This synthesis of the data provided the only good summary of the extant studies available on age and care giving effects.

Our aging population is growing rapidly, and the need for caregivers has been well established in the research community. Such need is illustrated by a study of individuals 65 years and older divided into two groups: those who were caregivers and those who were not. It was found that only half of the non-caregivers at baseline remained non-caregivers at a five-year follow up. The remaining caregiver group had either died, experienced the death of their spouse, transitioned into a care-giving role, or placed their spouse in a long-term care facility (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003). Engagement in care-giving, as either a caregiver or care-receiver would seem to be an inevitable part of growing older.

## Gender

There is a body of care-giving literature that explores gender differences in the care-giving role, although the findings of these studies are not definitive. Some studies have found that the impacts of gender are significant (Yee & Schulz, 2000). Other studies suggest that such research findings may reflect the tendency of women to more readily report poor health than men, thereby causing women to present as more affected caregivers (Vitaliaon, Scanlan & Zhang, 2003). As well, theories are cited as influencing the perceptions of gender differences in care-giving literature. For instance, women are believed to be socialized for care giving roles (Stoller, 1994), while men are not expected to engage as easily in the role of caregiver, since it is perceived to be a more feminine than masculine role (Fuller-Jonap & Haley, 1995).

The literature explores the impact of gender on caregiver health. In a study looking at the impact of chronic illness on the health and well-being of older caregivers, the gender of the caregivers was shown to have a significant association with anxiety and depression, with female caregivers more affected than males

(Lieberman & Fischer, 1995). Research also indicated that male caregivers have difficulties assuming personal and household responsibilities, but express experiencing the same amount of burden or less than female caregivers (Gregory, Peters & Cameron, 1990).

The research generally presents women as more affected psychosocially by the care-giving role (Sisk, 2000), with neither gender being more affected physically than the other, although some research indicates that men show greater changes in physiologic stress responses than women (Earle, Linden & Weinberg, 1999). This might predispose men to greater stress responses while in the role of caregiver. Given the strong role of women as caregivers in society, the bulk of care-giving research has tended to focus on female caregivers. However, due to concerns over the application of such research to males (Shanks-McElroy & Strobino, 2001), and in response to the anticipated increasing number of men who will be called upon to care for their older partners (Fuller-Jonap & Haley, 1995), there is a growing body of research looking specifically at men as caregivers.

The literature reflects gender differences in a variety of different ways, such as in attitudes towards services, informal care and the acceptance of government services. A higher proportion of men than women indicated a preference to use community services over asking family members for help, while a larger percentage of women than men believed that the government should provide more services (Laditka, Pappas-Rogich & Laditka, 2001).

Although interesting, these comparisons do not allow conclusions to be deduced on the influence of gender on care-giving.

A meta-analysis reviewing studies on gender differences in caregiver stressors, social resources, and caregiver health, found the differences between genders to range from small to very small. In the analysis, women were found to have slightly higher levels of burden and depression, and slightly lower levels of subjective well-being and physical health. Women also reported their care recipients had more behavioural problems, they provided more care-giving hours, helped more often with care-giving tasks, and assisted more with personal care (Pinquart & Sorenson, 2006). While review of the literature may suggest significant differences in care-giving health outcomes due to gender,

meta-analysis of studies did not indicate large differences between men and women in the care-giving role, and therefore it may be that both genders are equally at risk for experience of physical injury.

## Disposition

As discussed earlier in this literature review, psychological distress in the form of caregiver burden and depression is correlated with an array of physiological changes - all of which can lead to significant health issues and impairment (Patterson & Grant, 2003; Vitaliano et al, 2003). The literature exploring caregiver health documents the challenge of identifying pre-existing issues, prior to the caregiver being identified for the study. In other words, there is difficulty in understanding the state of caregiver health prior to their engagement in research on caregiver issues. As a result, a pre-disposition to depression or to a negative outlook may precede the diagnosis of health changes such as depression or activity restrictions arising from the caregiver role.

Although there are studies that suggest links between disposition and caregiver health, disposition, as a factor in care-giving, is not thoroughly explored in the literature. A ten year study of older caregivers who provided informal care to family members with Parkinson's disease found that caregiver pessimism early in the caregiver role predicted poor current and future caregiver health. Moreover, the beneficial contributions of optimism were not as great as the deleterious effects of pessimism (Lyons, Stewart, Archbold, Carter & Perrin, 2004). Coping styles, or disposition to respond to care-giving in certain ways, have also been explored as a means to predict responses to the care-giving role. A study examining the relationship between alcohol use and the amount of stress experienced by persons who provided care giving to people with dementia found that certain coping strategies pre-disposed caregivers to increased alcohol consumption (Knight, 1992).

The literature documents greater negative health effects among older caregivers who characterize themselves as being strained (Schulz, Newsom, Mittelmark, Burton, Hirsch & Jackson, 1997). Some findings indicate that perceptions of caregiver emotional strain are the best predictors for poor perceptions of health and limited functional performance on daily tasks (Mui, 1995).

In summary, there is insufficient information on the characteristics of caregivers prior to their engagement in care-giving to draw definitive conclusions with respect to the interrelationship of a caregiver's disposition and the impact of care-giving. Therefore, it is difficult to surmise the effect that disposition may have on risk of caregiver injury.

## Ethnicity

Ethnic groups are defined by common history, language, values and beliefs, customs and a common place of origin (Alonso, 1994). While most of the care giving literature has explored the experience of White caregivers, a body of literature explored the impact of ethnicity on the care giving experience. This interest is attributed to the anticipated changes in the demographics of older populations in many countries due to emigration and birth rate differentials.

The immigration policy of Canada will produce an annual increase in minority populations of 1.0%. Due to this growth rate, Canada's minority groups are anticipated to grow by six million people by 2070. Much of Canada's population is, and will continue to be, made up of people from many different countries of origin, with people currently identifying themselves as coming from among 22 different ethnic origins, and six visible minorities according to 2006 Canadian Census Statistics.<sup>1</sup>

One feature of the literature associating the health impacts of ethnicity with care-giving was the imperative of understanding the experiences of these minority groups, and in particular, their predisposition to certain health risks prior to engaging in the care-giving role (Ferraro, Farmer & Wynbraniec, 1997).

The performance of care-giving may be unique in every culture. Study has shown that the care-giving stressors used to predict health outcomes amongst White caregivers were not effective predictors amongst African-American participants. Instead, African-American participants were influenced by cultural beliefs that were unique to their ethnic group (Dilworth-Anderson, Goodwin & Williams, 2004; McDonald, Fink & Wykle, 1999). In another study evaluating the patterns of care-giving amongst older women of Anglo-Saxon descent, it was found that cultural patterns of care-giving influenced the

<sup>1</sup> <http://www.recensement2006.ca/english/census06/data/highlights/ethnic/pages/Page.cfm?Lang=E&Geo=PR&Code=01&Table=1&Data=Count&StatRec=1&Sort=2&Display=Page> Retrieved October 21, 2009.

health of the women, and that the women adhered to patterns of care-giving developed through adherence to patterns of enculturation when caring for their older disabled husbands (Cameron, 1990). Finally, an ethnographic study of ten elderly Korean couples evaluated the patterns of mutual caring, which indicated that cultural beliefs dictating engagement and the presence of a support system were the primary requirements of elderly couples in their care-giving and care-recipient roles (Ahn & Kim, 2007).

This literature illustrates differences that may be found within caregivers who have been raised with differing ethnic norms. A caregiver may experience conflict when living in a country with Western beliefs, and without the traditional cultural support networks (Holroyd, 2005). For instance, the literature references the effects of different norms or social issues of caregivers with different ethnic backgrounds, which contrast with the experiences of White caregivers, such as determining who is appropriate as a caregiver (Kipp, Tindyebwa, Karamagi, & Rubaale, 2007).

A meta-analysis of 116 articles evaluating the psychosocial impact of ethnic differences, stressors, and resources was located for this literature review. The findings concluded that, in comparison to studies of White caregivers, ethnic minority caregivers reported providing more hours of care, having fewer financial resources, less educational training, and using more informal support (i.e. family, friends) to assist in their care-giving tasks. Ethnic caregivers were also found to be better off psychologically with respect to care-giving stressors in comparison to White caregivers, although ethnic care-givers were at a disadvantage physically. This psychological advantage related to care giving stressors was primarily found within studies of African-American people; whereas Hispanic and Asian caregivers were found to have worse psychological health outcomes than White people (Pinquart & Sorenson, 2005).

The findings from this meta-analysis indicate that ethnic differences vary between groups (Dilworth-Anderson & Anderson, 1994). Ethnicity is a factor which should be explored when investigating caregiver injury, as culture is an important aspect in understanding the risks associated with care-giving.

## Significant gaps

It should be noted that for the countries with Aboriginal (Metis, First Nations and Inuit peoples) and Indigenous populations, with the exception of Australia, no literature was located which explored the care-giving experience within these cultures. The Australia Carers Association (2009) has explored the experience of Indigenous Australians, with the view that the health and wellbeing of family caregivers is crucial to the long-term health of regional and remote Indigenous communities. A caregiver impact statement, developed by Carers Australia was developed to influence Government policy regarding Indigenous communities. In this way Carers Australia hoped to effect change and thereby avoid negative outcomes for caregivers within these communities.

The limited findings on knowledge regarding Aboriginal and Indigenous caregivers are considered significant. Aboriginal and Indigenous populations have well-identified health concerns, and caregivers are known to play a critical role for people with chronic illness and disability in every society.

## Personal factors that increase risk of poor caregiver health

For this literature review - with the exception of some limited meta-analyses – the studies were found to cover a range of topics, generally focused on defining caregivers with certain characteristics as being more or less vulnerable to the impact of care giving. While none of the literature addressed the issue of physical injury directly, these characteristics are associated with caregiver health, and therefore may be associated with risk for injury.

These characteristics included:

- **Age** – meta-analysis found that increasing age was a factor that predisposed caregivers to negative health consequences;
- **Gender** – literature has assumed that women are more affected; however, a growing body of literature on the experiences of men, including a meta-analysis, indicates that physical and psychological differences are small to very small;
- **Disposition** – few studies examined this characteristic however, indicators exist which suggest that an individual's disposition to certain responses in care giving may lead to negative health behaviours;

- **Ethnicity and other significant gaps in the literature** – this is a growing area of concern given emerging demographics. Studies show that those caregivers belonging to certain ethnic groups do better psychologically than Whites, although Hispanic and Asian caregivers fair worse. Physically, Whites seem to experience the lowest negative physical impacts as caregivers. Significant gaps exist, as group studies are extremely limited, with no study recorded on Aboriginal or Indigenous groups.

## What are the contributing factors to impairments and activity limitations and/or participation restrictions?

A different pattern for health, depression, and coping can emerge when caregivers are grouped according to life circumstances. Studies suggest that relationships may exist between the impact of participating in care giving roles and external factors (Wright, 1994). Review of the literature revealed a large variability in the methodologies developed to explore the relationship between external factors and their effect on caregiver health. For the purpose of this literature review, the contributing factors were categorized as:

- Care-recipient characteristics, such as illness or duration of care giving;
- Socioeconomic factors; and
- Geographic location of the care giving setting.

Also included were studies on the effects of resources and intervention factors on caregiver status. It should be noted that - as in so many other areas of the literature - the studies were frequently found to discuss caregiver health in relation to a wide range of factors; therefore, contributing factors were often difficult to separate from other issues under examination.

### Care recipient characteristics

In looking at the impact of chronic illness on the health and well-being of spousal caregivers of partners with dementias, it was found that the more severe the illness, the higher were the spouses' anxiety and/or depression and physical symptoms, and the lower was their reported well-being (Lieberman & Fischer, 1995). Findings such as these are congruent with the general care-giving literature, found earlier

in this report. While caregivers are often found to report the impact of care giving on their own health and well-being, caregivers of people with dementias undergo the most significant exposure to health impacts (Lyons et al, 2004; Pinquart & Sorenson, 2003). Additionally as highlighted above, the duration of care-giving has an impact on the health of caregivers. Study has also concluded that length of care has an influence on the amount of burden perceived by participants, with those providing care for longer periods of time expressing greater burden. (Gaynor,1988).

There are inconsistencies in caregiver reporting when quantifying the health impacts of care-giving. In general, many caregivers report experiencing very negative effects on their mental health arising from care-giving, yet others do not report similar experiences. In one area of the literature, it has been proposed that these differences in reporting are not simply attributable to the amount or type of care provided (Savage & Bailey, 2004). Rather, there are other factors in the relationship between caregiver and care-recipient relationship that may be culpable. For instance, the type of relationship between the caregiver and the care-recipient has been found to affect the overall experience of care giving. Schulz, O'Brien, Bookwala, and Fleissner (1995) found that being the spouse of a care-recipient predisposed these caregivers to depression. In fact, an Australian study looking at comparisons of satisfaction within the caregiver role, found that parents were predisposed to report more positive associations with the caregiver role than were spouses. It also reported that spouses of care-recipients reported more satisfaction with the care-giving role than did children who acted as caregivers (Schofield, Bloch, Herrman, Murphy & Nankervis, 1998).

Such research suggests that there are many complexities in the relationship between caregiver and care-recipient, which may influence the health of both the caregiver and care-recipient. For example the care-giving relationship may influence reporting of injuries sustained while care-giving as different from being viewed as merely an injury that is sustained during normal duties.

Another study sought to explain the relationship between disabled elderly veterans' functional status and the level of strain on the caregiver. Major findings were:

- 52% of caregivers experienced significant strain;
- 59% care receivers were cognitively impaired to some extent, and were severely impaired in ADL and IADL; and
- The relationship between care receivers' functional status (cognitive, ADL, IADL) and caregiver strain were statistically significant (Marchi-Jones, Murphy & Rousseau, 1996).

A study whose purpose was to determine the needs of family caregivers to frail elderly care recipients found that more than two thirds of caregivers were spouses, and about 85% had health problems that affected their care giving. Ninety-eight percent of caregivers lived with the care recipient and the cumulative stress from their continuous involvement had affected their lifestyle, with more than 58% feeling that the care recipient needed more care than they could provide. More than 68% of the care givers were seniors (Abraham & Berry, 1992).

These findings indicate that characteristics of the care-giving relationship, such as severity of illness of care recipient, duration of the illness, the relationship of caregiver to care recipient, and care recipient functional ability, may factor as contributors to the health status of caregivers, and therefore may be factors influencing likelihood of physical injury in the caregiver.

## Socioeconomic

Socioeconomic factors have not been looked at closely in the literature of caregiver health. Typically, socioeconomic factors are one of many factor categories considered, although not focused solely upon, in studies of caregiver health. For instance, in a study researching the impact of age, socioeconomic status, and the degree of care giving, it was found that older caregivers held lower socioeconomic status, and were more likely to experience poor health (Pinquart & Sorenson, 2007).

In another study evaluating the experience of burden amongst older caregivers, it was concluded that as well as depending on the behaviour of the person cared for their own health, and their sense of coherence, a poor economic situation was part of predicting low scores on health and well being measures with caregiver (Ekwall, Sivberg & Hallberg, 2007).

While socioeconomic factors are recognized as an important factor in health, in the care-giving

literature linking health and well-being of caregivers to factors in care-giving, it is not a factor that has been adequately addressed within its own right, and should be explored as a factor when looking at risks for physical injury in the older caregiver population.

## Geographic

The setting in which care-giving takes place has been identified as an issue in the care-giving literature. Access to services is of great concern to researchers, as rural settings may not have similar resources to those that are available to older urban people, including knowledge on health promotion by caregivers which is important to maintain health, delay disease, and disability (Lee, 2006). Additionally comparisons between health of caregivers located in rural settings with that of the general population have shown that rural caregivers report statistically significant levels of lower perceived health status than the general population (Sanford & Townsend-Rocchiccioli, 2004).

A comparison of health promotion behaviours between older rural and urban spousal caregivers was conducted. The findings indicated that rural women reported significantly more barriers to positive health behaviours than urban women (Lee, 2006). Additionally, in a study on health promotion behaviours of older spousal caregivers, it was found that the most frequently reported health promotion behaviours were related to interpersonal relations, spiritual growth, and stress management. The least reported was physical activity, with rural women reporting significantly more barriers to physical activity than urban caregivers (Lee, 2006). As well, in evaluating participation in health promotion activities with rural elderly caregivers, it was found that emotional health was a significant positive correlate of engagement in health promotion activities. This finding suggests that emotional health is an important factor for a healthy lifestyle in the rural elderly caregiver (Easom, 2003).

The literature indicates that the location in which an older caregiver lives may influence their health, with a resultant impact on their participation in health promoting behaviours, and another possible factor in risk for physical injury while care-giving.

## Resources and interventions

The creation of resources to alleviate the stress of care-giving is cited as having the potential to improve

the caregiver's quality of life (Markowitz, Guterman, Sadik & Papadopoulos, 2003; Ross & Graydon, 1997). These resources have also been associated with increased caregiver mental functioning, perceived quality of patient care, and fewer patient behavioural symptoms (Markowitz, Guterman, Sadik & Papadopoulos, 2003).

There is, however, information on the various interventions and resources used with caregivers in general, with some focus upon specific subgroups (Finlayson, Dahl, Garcia & Preissner, 2008). As in other areas of caregiver literature, research on "uses of resources" is not conclusive. There were found to be some mixed reports on outcomes of resources and interventions when applied in care giving situations. For instance, one study evaluated the impacts of chronic illness on the health and well being of family members. This study suggested that the provision of services, whether in the form of home support or external community and/or professional services were not all positive. In some instances, services provided to the care-recipient could only be associated with a decrease in the physical symptoms of the care-recipients' adult children, and not with the care-giving spouse. When services were directed at both the caregiver and care-recipient, the results seem to correlate with an increase in anxiety and depression amongst the adult children. Overall, services were associated with significant differences in physical and psychosocial health for adult children of the care-recipient only. Positive outcomes for the caregiver and care-recipient were not significant (Lieberman & Fischer, 1995). This study shows how chronic illness affects the whole family beyond just the caregiver-care-recipient dyad. It also indicates that providing services and interventions may not meet the direct needs of the caregivers and care-recipients.

Despite often-conflicting reports on the needs of caregivers found in the literature, it has been established that caregivers are frequently in need of support with both the psychosocial and the daily demands of providing care. There is large variability within caregivers, and the individual needs of caregivers are not yet well understood. Despite this, there are a number of resources and interventions that have been developed to support caregivers with the aim of meeting their health needs and the needs of care recipients. Caregiver interventions may be categorized as being directed at reducing the objective amount of care

provided by caregivers – for example, by providing respite services. Alternatively, the interventions may be categorized as being directed at improving caregiver wellbeing through development of coping skills.

A meta-analysis, looking at six categories of typically used interventions, provides a synopsis of the research literature that analyzed these interventions. The meta-analysis analyzed the effectiveness of the following interventions:

- Psycho-educational interventions – this approach provides a structured program, which educates caregivers on the care receiver's disease and prognosis, the resources and services available, and provides skills training for caregivers. Such education demands a good understanding of the caregiver situation, so that the information can be tailored to best meet the needs of each caregiver situation (Schulz, Smyrnios, Carrafa & Schulz, 1994).
- Supportive interventions – are support groups focused around the caregiver experience, led by a professional or a volunteer, and which are meant to allow for the sharing of information and ideas amongst peers (Gonyea & Silverstein, 1991);
- Respite/adult daycare – is care often provided in a hospital setting, allowing caregivers to have a break from long-term care tasks. Care is provided by caregivers at the site, and may involve therapeutic interventions for the care receiver. For instance, nursing, occupational and physical therapy may be a part of the care recipient's needs. In addition, there is the opportunity for the caregiver to develop a therapeutic relationship with professional caregivers, and this may allow for the education of the caregiver to support healthy outcomes for both caregiver and care recipient (Hasselkus, 1983; Zarit, 1994);
- Psychotherapy – is a therapeutic relationship between a caregiver and a professional using cognitive-behavioural strategies to teach caregiver coping strategies, such as developing problem solving behaviours (Goldberg & Wool, 1985);
- Care-receiver training – this intervention type includes memory clinics (LoGiudice et al, 1999), and activity programs aimed at improving the care receivers performance on tasks (Sorenson, Pinguart, Habil & Duberstein, 2002); and

- Multi-component interventions – which may include mixed combinations of any of the above interventions.

This meta-analysis found that each of the interventions were effective at alleviating burden and depression in the caregivers, increasing their general self-reported well-being, and increasing caregiver knowledge. These effects were seen to persist for an average seven months after initial administration of the interventions (Sorenson, Pinqart, Habil & Duberstien, 2002, p. 369). These results also suggested that while the interventions provided generally positive outcomes for caregivers, some interventions had more specific effects. This suggests that clinicians and caregivers should define the desirable outcome and choose interventions that will best achieve the goals of intervention. In addition, it was found that different subgroups had different responses to specific interventions. For instance, spousal caregivers were found to benefit less than adult children caregivers and caregivers to people with dementia benefited less from interventions in comparison to those caring for people with other conditions (Sorenson et al, 2002). When looking at ways in which to influence the risk for caregiver injury, careful evaluation of interventions will need to take place, to ensure that services provide the desired effects.

These indicators reveal that while interventions commonly employed with caregivers and care-recipients may be effective, they should be tailored to meet the specific needs of high-need caregiver groups, such as spousal caregivers to partners diagnosed with dementia. Understanding the requirement to tailor interventions to the needs of the caregiver and care recipient is already well understood (Silliman, 1993). Corcoran (1992) reports on the provision of home-based occupational therapy interventions with caregivers of dementia sufferers. The need to collaborate with the caregiver to understand and properly address care issues is discussed, with emphasis placed on building skills relevant to the unique care situation (Corcoran, 1992).

The need to understand the unique needs of caregivers is also seen in literature documenting the development of an occupational therapy educational program for caregivers of aging people living with Multiple Sclerosis – a degenerative neurological condition (Finlayson et al, 2008). In the study, the needs of the caregivers were described as diverse.

A program was developed to meet the diversity of caregiver needs. It incorporated tools and strategies that could be used by the caregiver according to their specific needs, thereby addressing their own health needs and those of the care-recipient in a more effective manner. This process was presented as a “process that can be replicated to develop occupation based educational programs for other client groups” (Finlayson, Garcia & Preissner, 2008, p. 15).

Evaluation of this program showed no significant gains within the caregiver group when measured quantitatively; however, caregivers did report qualitative gains (Finlayson & Cho, 2009). Such outcomes suggest that client needs are complex, and that research on interventions and the development of relevant supports need to continue, so as to best support and provide crucial services to this vulnerable population.

Many references were made in the literature of caregivers who did not access or fully utilize resources and services (Laditka, Pappas-Rogich & Laditka, 2001). In a study looking at attitudes towards service use amongst spousal caregivers of frail older veterans, it was found that most caregivers agreed that it is acceptable to get help with the physical care of the husband and to get help themselves for the emotional strain caused by care giving. The self reports by caregivers of their likelihood to use services were found to be a positive predictor of the number and frequency of service use. When caregivers took the attitude that services only used as a last resort, this proved to be the strongest and most consistent negative predictor of both the number of services used and the frequency of service use (Dorfman, Berlin & Holmes, 1998).

Caregivers have also been reported as wanting more information about a range of professional services and other facilities, including a central repository for information storage, access and retrieval and local, flexible respite services (Chambers, 1992). This range of information suggests that there is a requirement to meet the needs of caregivers as individuals, with needs that are as unique as their care-giving situation, such as in decreasing risk for physical injury.

## Contributing factors that increase risk of poor caregiver health

There were found to be many ways in which the relationships between external factors and their effects on caregiver health were explored, which, while

not documented as such, may be contributors to risk of physical injury. Possible contributing factors are concluded to be:

- Care recipient characteristics - characteristics of the care-giving relationship, duration of illness, relationship to care recipient, and function of the care recipient;
- Socioeconomic factors – while not well developed, this factor appears to be linked to caregiver health and well being;
- Geography - the location in which an older caregiver lives may influence participation in health promoting behaviours;
- Resources and Interventions - the creation of resources to alleviate the stress of care-giving is cited in studies as having the potential to improve caregiver quality of life (Markowitz et al, 2003; Ross & Graydon, 1997). They have also been associated with increased caregiver mental functioning, perceived quality of patient care, and fewer patient behavioural symptoms (Markowitz et al, 2003).

## Conclusions: Implications for practice, policy, research and education

Understandings of the health impact of care-giving, and therefore the potential for sustaining physical injury as a caregiver, are not yet well defined. The literature presents care-giving as having both multi-factorial and multidimensional impact on the caregiver (Shaw et al, 1997). Informal care-giving relationships are often defined as vulnerable because of the many factors influencing the caregiver, thereby predisposing the caregiver to physical injury. To understand the implications of care-giving on caregiver health, one must first understand the many factors that influence the caregiver. As the literature shows, these factors include a multitude of interactions between the individual caregiver characteristics with those of both the care receiver and the care environment. Although not well defined, some research suggests that the issues of older caregivers are far more complex than those for other groups, due to the higher risk of caregiver health problems (McGarry & Arthur, 2000).

Despite the tremendous diversity in persons and care contexts, the literature indicates that older adult caregivers may be predisposed for sustaining health

issues through participation in care-giving. To enable continued engagement with the occupation of care-giving sustainable solutions aimed at injury prevention and health promotion are required. In answer to this need, **it is recommended by CAOT to the Division of Aging and Seniors for:**

- **Education of health professionals, such as occupational therapists:** Promotion of caregiver health through use of screening tools and resources to support caregivers in their role will enable health care professionals to identify and appropriately support the caregiver throughout their care-giving.
- **Screening of caregivers for risk of neglect and abuse:** Literature specifically addressing issues of neglect and abuse of older caregivers was not located for this literature review. However, older caregivers are part of a demographic identified as at risk for neglect and abuse; therefore the older adult caregiver should be screened for potentially dangerous or negative care situations.
- **Monitoring of caregivers for changes in health status:** Monitoring of caregiver health status will allow for identification of the potential for negative impacts resulting from participation in care-giving, such as caregiver injury.
- **Development of supports and health promotion services:** To enable older adult caregivers to provide effective care-giving free of injury, they should be assessed for and have access to appropriate services, such as respite care and caregiver training. Our society cannot afford to lose this informal caregiver cohort.
- **Informing caregivers of their rights:** While raising awareness of potential for risks, awareness of rights as caregivers will facilitate older adults with engagement in health promotion and injury prevention strategy.
- **Recognition of the contributions of caregivers:** Caregivers provide a valuable service to society. By recognizing their contributions it will facilitate general social support of the rights of caregivers to health, well-being, and safety while providing care.
- **Development of best practices and health promotion policy through:**
  - Pan-Canadian approaches to caregiver health and well-being with coordination among governmental departments, municipal and provincial health authorities, and non-governmental groups,

- Consulting standards already set by the International Plan of Action on Ageing and the conventions, recommendations and resolutions of the International Labour Organization, the World Health Organization and other United Nations entities. These documents will assist in developing understandings of caregiver rights in the capacity of their care-giving service provision.
- Consultation with groups such as International Federation on Ageing (IFA), an international non-governmental organization consisting of NGO, corporate, academic, government, and individual membership. The aim of the IFA is to generate positive change for older people, through knowledge dissemination practices

**While recognized as not being within the mandate of the Division of Aging and Seniors, CAOT also recommends:**

- **Screening of caregivers:** Risk of physical injury, declining health, financial hardship, neglect, and abuse all need to be identified to ensure the health and well-being of the caregiver.
- **Access to service:** Services such as caregiver training, income support, family and community support and self-help (groups, hotline), social and legal services, and institutional care must be developed and promoted to caregivers as supports enabling their health and well-being.
- **Initiation of a collaborative policy response:** Development of a collaborative policy response from governments on care-giving and in support of care-giving, will ensure that social systems and processes recognize and support the contributions of caregivers.

## Further study

Within the extant literature addressing informal care-giving, age is either not considered a factor, or the age of study participants is not clear. This issue has been identified within the literature (Thornton, 1989; McGarry & Arthur, 2000). Research on interventions with specific subgroups, such as older caregivers, using the best evidence and client-driven approaches are supported by the literature. Review of the literature also showed that while often referred to as an issue, existing research focused specifically on older people within caregiver roles is very limited. As well, few studies identify the physical impacts of engaging in

care-giving. An important part of future research will be the identification and tracking of older caregivers, and the injuries sustained as a result of their engagement in the caregiver role.

*“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.”*

Rosalynn Carter,  
Former First Lady,  
United States

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**CAOT - ACE**

Canadian Association of Occupational Therapists  
CTTC Building, 3400 - 1125 Colonel By Drive  
Ottawa, Ontario K1S 5R1 Canada  
(800) 434-2268 • [www.caot.ca](http://www.caot.ca)