Western University Scholarship@Western

Electronic Thesis and Dissertation Repository

6-6-2017 12:00 AM

Social Support, Social Participation, and Depression among Caregivers and Non-Caregivers in Canada: A Population Health Perspective

Jovana Sibalija, The University of Western Ontario

Supervisor: Dr. Marie Savundranayagam, *The University of Western Ontario* A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences © Jovana Sibalija 2017

Follow this and additional works at: https://ir.lib.uwo.ca/etd

🗳 Part of the Other Mental and Social Health Commons

Recommended Citation

Sibalija, Jovana, "Social Support, Social Participation, and Depression among Caregivers and Non-Caregivers in Canada: A Population Health Perspective" (2017). *Electronic Thesis and Dissertation Repository.* 4638. https://ir.lib.uwo.ca/etd/4638

This Dissertation/Thesis is brought to you for free and open access by Scholarship@Western. It has been accepted for inclusion in Electronic Thesis and Dissertation Repository by an authorized administrator of Scholarship@Western. For more information, please contact wlswadmin@uwo.ca.

Abstract

Caregivers report higher depression levels than non-caregivers. Depression is a major concern because it predicts poor health. Poor caregiver health negatively impacts care provision and increases institutionalization risk for the ill relative. Social support and social participation can influence depressive symptoms in caregivers, with low levels linked to higher depression scores. Previous studies used small, non-Canadian samples. The present study used population-level data from the Canadian Longitudinal Study on Aging to investigate the relationships among social support, social participation, and depression in caregivers and non-caregivers. Analysis of variance assessed differences in the means of the social variables and depression. Path analysis examined the relationship between the social variables and depression. Caregivers reported significantly higher levels of social support and social participation versus non-caregivers. Higher levels of affectionate social support and social participation were associated with lower depression scores. The study identifies the type of social support beneficial for caregivers.

Keywords: informal caregiving, social support, social participation, depression

Acknowledgements

Though one name appears on this thesis, the completion of this work would not have been possible without the support and assistance of many individuals. I would like to thank my supervisor, Dr. Marie Savundranayagam, for all of her support and time spent teaching and mentoring me. I would have never considered a career in research were it not for your encouragement to give research a chance and for the guidance you provided throughout my undergraduate and graduate years. Thank you for believing in me and pushing me to do more than I thought I could. I would like to thank the members of my advisory committee, Dr. JB Orange and Dr. Marita Kloseck, for their valuable feedback on this thesis. To the wonderful friends I have made in this program, thank you for your words of wisdom and encouragement. I feel very fortunate to have been in the presence of such supportive and inspiring peers. Lastly, I would like to thank my family for their tremendous amount of support and encouragement. The completion of this thesis would not have been possible without you.

Table of Contents

Abstract	ii
Acknowledgements	iii
Table of Contents	iv
List of Appendices	v
List of Tables	vi
List of Figures	vii

Chapter 1: Introduction	1
The Aging of the Canadian Population	1
The Increasing Prevalence of Chronic Disease in Canada	2
Caring in an Era of Fiscal Restraint	2
The Consequences of Informal Caregiving	5
Caregiving and Depression	5
The Mediating Role of Social Support and Social Participation	7
Conclusion	8

Chapter 2: Literature Review	9
Informal Caregiving	9
Caregiving in Canada	10
The Consequences of Caregiving	15
Caregiver Depression	16
Predictors of Depressive Symptoms in Caregivers	17

Caregiving and the Stress Process	23
Constriction of a Caregiver's Social Life: The Impact on Social Support and Soc	cial
Participation	25
The Activity Restriction Model of Depressed Affect	29
Caregiving and Activity Restriction	30
The Caregiving Factors that Influence Activity Restriction	32
The Nature of the Relationship between the Caregiving Dyad	32
The Demands of Caregiving	36
Activity Restriction and Role Engulfment	38
How Changes in Caregiving Influence Activity Restriction	41
Conclusion and Statement of the Problem	43

Chapter 3: Method.	45
Canadian Longitudinal Study on Aging	45
Research Design	46
Inclusion Criteria	47
Exclusion Criteria	47
Measures	47
Social Support	47
Social Participation	49
Depression	50
Demographic Information	50
Caregiver Status	50
Age	51

Gender51
Education
Perceived General Health
Perceived Mental Health52
Income
Data Analysis
Analysis of Variance
Path Analysis53
Chapter 4: Results
Sample Description
Assumptions of Linear Regression
Normality60
Homoscedasticity and Linearity
Multicollinearity
Differences in the Means of Social Support, Social Participation,
and Depression
Path Analysis
Chapter 5: Discussion
The Impact of Social Support on Depression
Differences between Caregivers and Non-Caregivers in Social Support73
The Impact of Social Participation on Depression74
Differences between Caregivers and Non-Caregivers in Social Participation

Differences between Caregivers and Non-Caregivers in Depression	79
Limitations	81
Implications	82
Implications for Policy	83
Implications for Practice	84
Directions for Future Research	85
Conclusion	87
References	
Appendices	100
Curriculum Vitae	124

List of Appendices

Appendix	Item	Page
A	.Ethics Approval Form	100
В	.CLSA Education Measure	101
C	.CLSA General Health Measure	103
D	.CLSA Income Measure	104
E	.CLSA Social Support Availability Measure	108
F	CLSA Social Participation Measure	115
G	CLSA Depression Measure	120

List of Tables

Table 1: Description of Sample	.58
Table 2: Means and Standard Deviations by Caregiver Status on Study Variables	.60
Table 3: Pearson Correlations for Study Variables	62
Table 4: Mediation Model Examining the Effect of Caregiver Status on	
Depression by Social Support and Social Participation	67

List of Figures

Figure 1: Tested Path Model	54
Figure 2: Total Effect of Caregiver Status on Depression	64
Figure 3: Final Path Model	66

Chapter 1: Introduction

The Aging of the Canadian Population

Canada is experiencing population aging. In July 2015, Canadians aged 65 and older outnumbered children aged 0-14 for the first time in history (Statistics Canada, 2015). One in six Canadians were aged 65 and over, comprising 16.9% of the Canadian population (Statistics Canada, 2015; Statistics Canada, 2017). The proportion of older adults in Canada is expected to increase. By 2031, 1 in 4 Canadians will be aged 65 or older, comprising 23% of the population (Statistics Canada, 2017). This figure will increase to 25% of the population by 2056 (Statistics Canada, 2015; Taylor, 2014). It is important to note that the population growth rate for Canadians 65 and over is four times faster than the growth rate for the entire population (Statistics Canada, 2015). The faster growth rate for older adults can be attributed to the aging of the Baby Boomer population. The Baby Boomer cohort is currently the largest cohort in Canada. It consists of over 9 million Canadians born between 1945 and 1965 (Statistics Canada, 2011).

Certain age groups are growing faster than others in Canada. Individuals aged 85 and older represent the fastest growing age group in Canada. The population of Canadians aged 85+ experienced an increase in growth of 127% from 1993 to 2013. The number of Canadians 85 years and older grew from 309,000 in 1993 to 702,000 in 2013 (Taylor, 2014). In addition, Canadians aged 100 and older represented the fastest growth in the population from 2011 to 2016, experiencing an increase in growth of 41.3% (Statistics Canada, 2017). Individuals in the 85 and older age group report high levels of chronic disease and disability (National Institute on Aging, 2007; Taylor, 2014). There will be important consequences for health and social services in Canada as more individuals continue to reach the ages of 85 and older.

The Increasing Prevalence of Chronic Disease in Canada

As age increases, the likelihood of developing a chronic disease also increases (Canadian Institute for Health Information [CIHI], 2011; Denton & Spencer, 2010). In 2012, 85% of Canadians aged 65-79 and 90% of Canadians aged 80 and over exhibited at least one chronic condition (Taylor, 2014). The prevalence of chronic disease is increasing in Canada with prevalence rates rising by 14% each year (Elmslie, 2012; Taylor, 2014). While chronic conditions exert an impact on individual health, they also have important consequences for the health care system. Denton and Spencer (2010) found that individuals with more chronic conditions spent more time in hospitals and other health care institutions and had more consultations with healthcare professionals than individuals with fewer chronic conditions. For example, individuals with two chronic conditions spent four times as long in health care institutions compared to individuals with no chronic conditions. According to CIHI (2011), older adults with three or more chronic conditions reported three times the amount of healthcare resource use than older adults with no chronic conditions. These findings indicate that chronic diseases lead to increasing healthcare costs.

Caring in an Era of Fiscal Restraint

The increasing prevalence of chronic disease in Canada comes at a time when provincial and federal governments are decreasing healthcare spending. Since 2010 healthcare spending per capita has decreased by approximately 0.1% per year. The growth of health care spending has not kept up with population growth rates and inflation rates (CIHI, 2016). The reasons for this decrease in spending are the modest growth of the Canadian economy and the federal and provincial governments' focus on balancing budgets and reducing deficits (CIHI, 2016). The amount of money spent on healthcare varies by age group. Healthcare spending is highest for older adults in Canada. An estimated \$11,635 per person was spent on adults aged 65 and older in 2014 (CIHI, 2016). As well, spending on older adults increased as age increased. Per-person healthcare spending ranged from \$6,424 for Canadians aged 65 to 69 to \$21,150 for Canadians age 80 and older in 2014 (CIHI, 2016). The proportion of public healthcare spending on older adults has not increased drastically over the past decade. In 2000, older adults consumed 44% of all public spending on healthcare. By 2014, older adults consumed 46% of all annual public spending on healthcare. However, the proportion of older adults in the Canadian population increased from 12.6% to 15.7% from 2000 to 2014 (CIHI, 2016). The aging population and the increasing prevalence of chronic disease in Canada have forced federal and provincial governments to find ways to reduce healthcare costs. One such way to reduce healthcare costs is through an increasing reliance on the home care sector to deliver care.

Home care refers to services such as nursing, personal support, homemaking, and other related health, medical, rehabilitative and social support services performed in an individual's home (The Expert Group on Home Care, 2015). Home care services enable ill individuals to receive care while remaining at home. There has been an increase in the number of Canadians receiving home care services. For example, in 2015, the number of individuals receiving home care services from Community Care Access Centres (CCACs) doubled since 2003/2004 in Ontario (The Expert Group on Home Care, 2015). 715,500 Ontarians received home care services in 2015; with individuals aged 65 and older comprising 60% of home care clients (Auditor General of Ontario, 2015). This number is projected to increase as the population ages. Many of the individuals receiving home care

services are classified as high-need. These are individuals who require more intensive care over a longer period of time (The Expert Group on Home Care, 2015).

Although health, clinical rehabilitation and social care professionals deliver home care services, the family also plays a role in care delivery. In 2012, 90% of Canadians receiving home care services relied on a family caregiver. Family caregivers provided an average of 7 hours of care per week while home care services delivered 2 hours of care per week in 2012 (The Expert Group on Home Care, 2015). This finding demonstrates the vital role family caregivers play in helping ill individuals remain at home thereby optimizing personalized care while simultaneously reducing health care costs at acute, subacute, rehabilitation and long-term care facilities. Family caregivers assist with a wide variety of care tasks ranging from instrumental tasks such as assistance with household chores to personal care tasks such as bathing or dressing (Turcotte, 2013). The provision of instrumental and personal care activities means individuals receive care while remaining at home, thereby improving his or her quality of life (Czaja et al., 2009). The unpaid assistance family caregivers provide also brings benefits to the healthcare system. Family caregivers contribute approximately \$25 billion in savings across the health, community and social care systems (Alliance for a National Seniors Strategy, 2016; Hollander et al., 2009). However, the system is at risk of losing the benefits family caregivers bring. In 2013-2014, over one third of Ontario caregivers reported feelings of distress, anger, or depression, or were unable to continue providing care. The percentage of caregivers reporting these negative feelings has more than doubled, increasing from 15.6% in 2009-2010 to 33.3% in 2013-2014 (Health Quality Ontario, 2015).

The Consequences of Informal Caregiving

Being a family caregiver is associated with many negative physical and mental health outcomes. Caregivers are at an increased risk of cardiovascular disease, higher levels of stress, anxiety, and depression, and lower levels of subjective well-being and physical health compared to non-caregivers (Ho et al., 2013; Pinquart & Sörensen, 2003). Caregiving also is linked with an increased risk of death. Beach and Schulz (1999) found that spousal caregivers who provided care and experienced strain while caregiving had a 63% higher risk of mortality than non-caregivers.

Caregiving and Depression. Depression related to caregiving is a negative health outcome requiring attention because it is a predictor of functional decline and poor health status (Covinsky, Fortinsky, Palmer, Kresevic, & Landefeld, 1997; Shao et al, 2017). Poor physical and mental health can compromise a caregiver's ability to assist his or her family member. Caregiver depression has implications for both the caregiver and the individual to whom they provide care. Depression affects caregivers' health, which in turn affects their ability to provide care. A compromised ability to provide care affects the care and quality of life of the individual requiring assistance, increasing the risk of hospitalization or relocation to long-term care for the care-recipient (Czaja et al., 2009).

Multiple factors can influence depressive symptoms in caregivers. Demographic predictors of caregiver depression include age, gender, income, living arrangement, kinship and health. Younger caregivers and females report higher amounts of depressive symptoms compared to older caregivers and males (Arai, Kumamoto, Mizuno, & Washio, 2014; Luchsinger et al., 2015; Pinquart & Sorensen, 2011; Williams, 2005; Won, Ahn, & Choi, 2017; Young et al., 2008). Lower income is associated with higher depression scores (Arai et al., 2014; Cummings & Kropf, 2015; Kim & Lee, 2003; Kim, Carver, Rocha-Lima, & Shaffer, 2011; Miller et al., 2001; Pinquart & Sorensen, 2011; Schulz, Obrien, Bookwala, & Fleissner, 1995; Won et al., 2017). Caregivers who live with the individual for whom they are caring experience higher amounts of depressive symptoms compared to caregivers who do not co-reside with the individual requiring care (Arai et al., 2014). Spouses are more likely to report higher levels of depressive symptoms than non-spousal caregivers such as adult-children (Berg-Weger, Rubio, & Tebb, 2000; Cummings & Kropf, 2015; Pinquart & Sorensen, 2011; Schulz et al., 1995; Williams, 2005; Young et al., 2008). Poor caregiver health also is associated with higher levels of depressive symptoms (Arai et al., 2014; Cummings & Kropf, 2015; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Luchsinger et al., 2015; Miller et al., 2001; Piercy et al., 2013; Schulz et al., 1995; Williams, 2005).

Other predictors of depressive symptoms in caregivers include stressors related to caregiving. The severity of cognitive impairment of the individual requiring care and problem behaviours exhibited by the individual requiring care are two key stressors associated with caregivers' depressive symptoms. Examples of problem behaviours include resisting care, agitation and wandering. Family members who are caring for individuals with more severe cognitive impairment and for individuals who exhibit more problem behaviours report more depressive symptoms compared to those caring for an individual with milder cognitive impairment and fewer problem behaviours (Arai et al., 2014; Cummings & Kropf, 2015; Haley et al., 2003; Kim & Lee, 2003; Miller et al., 2001; Piercy et al., 2013; Romero-Moreno, Márquez-González, Mausbach, & Losada, 2012; Schulz et al., 1995). Caregiver burden also predicts depressive symptoms. The term caregiver burden refers to the impact of the physical, psychological, social and financial demands of caregiving on the caregiver (Pinquart & Sorensen, 2003) Caregivers who reported experiencing high amounts of burden had higher depression scores than caregivers with lower amounts of burden (Schulz et al.,

1995; Song, Biegel, & Milligan, 1997; Young et al., 2008).

The Mediating Role of Social Support and Social Participation

Social variables play important roles in buffering the effects of depressive symptoms in caregivers. For example, social support and social participation mediate depressive symptoms. Lower levels of perceived social support are associated with higher levels of depressive symptoms (Kim et al., 2011; Losada et al., 2010). In addition, social network size is a predictor of depression. Caregivers with larger social networks reported lower amounts of depressive symptoms compared to caregivers with smaller social networks (Haley et al., 2003; Piercy et al., 2013; Williams, 2005). Social participation also plays a role in influencing depressive symptoms in caregivers. Lower levels of social participation are linked with higher levels of depressive symptoms (Croezen, Avendano, Burdorf, & van Lenthe, 2015; Ghosh & Greenberg, 2012; Li, Seltzer, & Greenberg, 1997; Loucks-Atkinson, Kleiber, & Williamson, 2006; Mausbach, Patterson, & Grant, 2008). Mausbach and colleagues (2008) found decreasing participation in regular activities to be significantly associated with higher depression scores. Caregivers in the study reported more restriction in activities and exhibited more depressive symptoms than non-caregivers. As well, caregivers in the study with higher levels of activity restriction displayed higher depression scores compared to caregivers and non-caregivers with lower levels of restriction (Mausbach et al., 2008). The results of the study emphasize that depression is influenced by the extent to which caregiving impacts an individual's ability to participate in household and social/recreational activities such as recreational sports, socializing with friends and performing household chores. Loucks-Atkinson and colleagues (2006) reported similar findings in their longitudinal study on activity restriction in middle-aged and older caregivers. Restriction in instrumental activities, such as household chores, managing finances, doing laundry, making meals,

restriction in self-care activities, and restriction in expressive activities, such as socializing with friends, predicted higher levels of depressive symptoms one year later into the study. Restricting participation in instrumental and expressive activities at Time 1 also was associated with lower social support, lower perceived health status and increases in physical symptoms (Loucks-Atkinson et al., 2006). The findings from these studies highlight that social support and social participation can have an important influence on a caregiver's mental health.

Conclusion

Depressive symptoms in caregivers are influenced by a variety of factors including demographics, stressors associated with the act of caregiving, and social variables among other factors. Social support and social participation are two modifiable mediators of caregiver depression. Adjustments can be made to enhance social support and social participation for family caregivers. Examples of adjustments include providing respite so caregivers have time for themselves and providing caregivers with resources on how to seek support. While the literature on the impact of social support and social participation on caregiver depression is extensive, little information exists on this relationship among Canadian caregivers. Additionally, sample sizes in previous studies were small. The purpose of this thesis is to investigate the relationship among social support, social participation and depression in caregivers and non-caregivers using population-level data from the Canadian Longitudinal Study on Aging (CLSA).

Chapter 2: Literature Review

Informal Caregiving

Informal caregivers are individuals who provide unpaid assistance to relatives or friends who are unable to care for themselves (Corvin et al., 2017; Pearlin, Mullan, Semple, & Skaff, 1990). They are contrasted with formal caregivers who are defined as individuals who are paid to provide care such as physicians, nurses, and personal support workers (International Federation on Ageing, 2014). The term caregiver will be used throughout the following literature review segment and will refer to informal caregivers. Informal caregivers assist with numerous activities ranging in intensity from instrumental care tasks to personal care tasks. Instrumental care tasks include activities such as providing transportation, cooking meals, and assisting with household chores. Personal care tasks involve assistance with activities of daily living such as dressing, toileting, and bathing (Hollander et al., 2009). The provision of instrumental and personal care activities by caregivers enables individuals to receive care while remaining at home, thereby improving their quality of life (Czaja et al., 2009).

A hierarchy exists in the provision of informal care to older adults. The majority of informal caregivers are spouses and adult-children, with wives and daughters/daughters-in-law providing more care compared to husbands and sons/son-inlaws (Pinquart & Sorensen, 2011). Differences exist in hours spent caring and the type of care provided between spouses and adult-children caregivers. Spouses spend more hours providing care and provide more intensive care compared to adult-children (National Alliance for Caregiving, 2015; Pinquart & Sorensen, 2011; Sinha, 2013). Differences in the amount of time spent providing care between spouses and adult-children are discussed in the section below on caregiving in Canada. Spouses are more likely to assist with personal care tasks such as dressing and feeding. Adult-children assist more with instrumental tasks such as providing transportation, and managing finances (National Alliance for Caregiving, 2015). One of the reasons for the differences in the amount and the type of care provided is that spouse caregivers are more likely to be living with their spouse who needs care and are more readily available to provide more intensive care versus adult-children who often live in another household and may also have their own family to whom they need to provide care (Pinquart & Sorensen, 2011).

Caregiving in Canada

The trends discussed above also reflect Canada's current population of caregivers. Approximately 8 million Canadians over the age of 15 are informal caregivers to family members or friends living with a chronic health condition, disability or aging-related needs. The majority of these caregivers are between the ages of 45 and 64 (Sinha, 2013). Women comprise more than half (54%) of caregivers in Canada. Of the individuals surveyed in the 2012 General Social Survey, 48% reported providing care to a parent or parent-in-law. Spouse caregivers comprised 8% of the sample. The remaining individuals in the sample reported providing care to close friends, neighbours, grandparents, siblings and extended family members, or sons and daughters. The majority of respondents (89%) stated that they had been providing care to an individual for a year or longer (Sinha, 2013).

Age-related needs of the family members or friends to whom the informal caregivers were looking after were reported to be the most common reason for a need for care. Caregivers spent a median of 3 hours per week providing care to family members or

friends. Providing transportation and assisting with household tasks were the most common tasks performed (Sinha, 2013). There were differences in the amount and type of care provided based on the caregiver's relationship to the person to whom he or she was providing care. Adult-children caregivers reported a median of 4 hours of care per week (Sinha, 2013; Turcotte, 2013). Spousal caregivers reported a median of 14 hours of care per week, more than any other group in the sample. Additionally, spouses comprised 31% of the group of caregivers who reported spending 30 hours or more a week on care provision (Sinha, 2013). Approximately 39% of spousal caregivers reported providing assistance with personal care tasks. In comparison, 15% of adult-children caregivers reported assisting with personal care (Turcotte, 2013). These findings support previous research, which indicates that spousal caregivers provide more care compared to other family caregivers (National Caregiver Alliance 2015; Pinquart and Sorensen, 2011).

Special attention must be paid to individuals who are employed and who also function as informal caregivers. Sixty percent of respondents in the General Social Survey reported balancing employment with caregiving duties (Sinha, 2013). Informal caregivers who were employed in paying positions reported disruptions to their work routines due to caregiving. Approximately 43% of employed caregivers stated that they were late to work, had to leave work early or take time off during the day to care for a loved one (Sinha, 2013). The proportion of individuals reporting disruptions to work because of caregiving increased as hours providing care increased. Approximately 54% of employed caregivers who provided 20 or more hours of care per week reported experiencing work disruptions (Sinha, 2013). Long-term implications of balancing employment with caregiving reported in the General Social Survey included reducing regular work hours, rejecting job promotions or new job opportunities, searching for less demanding employment, and experiencing reductions in household income (Sinha, 2013). These responses highlight the personal and economic impact informal caregiving has on caregivers' lives. Reducing work hours or turning down new job opportunities have the potential to reduce caregivers' income and benefits they may be eligible to receive through their employment, such as health insurance. Balancing employment with caregiving duties is more prominent for adult children because they are more likely to be employed compared to older adult spouses (Pinquart & Sorensen, 2011).

Informal caregiving is associated with economic losses on individual and societal levels. For example, informal caregivers can experience losses in personal income because of reduced work hours. This impacts productivity at a societal level because more individuals are spending less time at work because of caregiving duties. Reductions in work hours by employees result in slower and/or lower production and revenue generation for organizations and businesses. Lost productivity due to caregiving duties costs the Canadian economy an estimated \$1.3 billion annually (Canadian Caregiver Coalition, 2015).

Balancing caregiving and employment is an example of how caregiving duties can infringe on an informal caregiver's time for other activities. The findings from the General Social Survey on the topic of informal caregivers taking time off work during the day or leaving work early due to caregiving duties help demonstrate the impact of caregiving on other social dimensions of caregivers' lives. Length of caregiving and spending more hours providing care are associated with increases in objective burden (Savundranayagam & Montgomery, 2010). Objective burden refers to the extent to which caregiving imposes on the time a caregiver has for non-caregiving activities such as socializing with friends. Informal caregivers who spend more time caring and providing more intensive care, such as assisting with bathing or dressing, may not have the time to engage in many social or leisure activities beyond caregiving compared to caregivers who provide fewer hours of care and assist with less intensive care tasks. The amount of objective burden placed on caregivers' lives can impact the time caregivers have for themselves and their ability to engage in desired non-caregiver related activities.

Informal caregivers are invaluable to the Canadian healthcare system as the unpaid assistance they provide enables individuals to whom they provide care to remain at home. In fact, it is estimated that informal caregivers contribute approximately \$25 billion in savings across the health, community and social care systems (Alliance for a National Seniors Strategy, 2016; Hollander et al., 2009. However, the system is at risk of losing the benefits caregivers bring. In 2013-2014, over one third of Ontario caregivers reported feelings of distress, anger, or depression, or were unable to continue providing care (Health Quality Ontario, 2015).

Caregivers are at an increased risk of depression compared to non-caregivers (Pinquart & Sörensen, 2003). Two important social variables can influence this risk. Social support and social participation are known to influence rates of depressive symptoms in caregivers. More perceived social support and higher levels of social participation are associated with lower depression scores among informal caregivers (Ghosh & Greenberg, 2012; Li et al., 1997; Loucks-Atkinson et al., 2006; Mausbach et al., 2008). However, little information exists on the relationships between social support, social participation, and depression among informal caregivers in Canada and sample

13

sizes in previous studies were small. Small sample sizes make it difficult to generalize study results to the general population. Generalizability is difficult because study samples may not be representative of the entire population and, as a result, study findings may not apply to the whole population. Population-level studies, such as the Canadian Longitudinal Study on Aging (CLSA), involve more representative, large samples. A major advantage of population-level studies is external validity. Larger sample sizes are more representative of the population of interest than smaller samples. As a result, the results of population studies can be generalized to the entire population (Szklo, 1998). Larger sample sizes increase statistical power, which is the ability to detect an effect, if an effect actually exists (Lin & Lucas, 2013). The increased statistical power of population-level studies also enables researchers to see and analyze smaller and more complex effects (Lin & Lucas, 2013). Population studies are often longitudinal, enabling researchers to make comparisons and notice differences over time (Lin & Lucas, 2013). As mentioned earlier, little research exists on the influence of social variables on depression in Canadian caregivers. Therefore, a study using population-level data is needed to investigate the relationships among social support, social participation and depression in Canadian caregivers.

The following segment of this literature review will focus on describing and discussing the relationships among social support, social participation, and depression in informal caregivers. The review will highlight the importance of the social variables' impact on depression in Canadian informal caregivers.

The Consequences of Informal Caregiving

Being a caregiver is associated with many negative physical and mental health outcomes. Caregivers are at increased risk of cardiovascular disease, of higher levels of stress, anxiety, and depression, and of lower levels of subjective well-being and physical health compared to non-caregivers (Chan, Malhotra, Malhortra, Rush, & Ostbye, 2013; Ho et al., 2013; Pinquart & Sörensen, 2003). Caregiving also is linked with an increased risk of morality. Beach and Schulz (1999) found that spousal caregivers who provided care and experienced caregiving strain had a 63% higher risk of mortality than noncaregivers. The study found caregiving to be an independent risk factor for death.

Caregiving also is associated with positive outcomes for caregivers. Caregivers report developing a closer relationship with the individual requiring care, experiencing personal growth, developing a sense of mastery over caregiving skills, and feeling useful and like they could give back to other caregivers (Cheng, Mak, Lau, Ng, & Lam, 2016; Li & Loke, 2013; Peacock et al., 2010). The provision of care to an ill family member creates a closer bond between the caregiver and his or her ill relative. Caregivers spend an increased amount of time with the individual requiring care, enabling the caregiver to know their family member in a new way and to gain a deeper appreciation for their relationship (Cheng et al., 2016; Li & Loke, 2013). Spousal caregivers also report that caregiving is a way to show their love for their ill spouse, deepening the relationship bond (Li & Loke, 2013). As well, caregiving provides caregivers with the chance to learn more about themselves, leading to personal growth. Examples of personal growth include learning how to cope with difficult situations, and showing more patience and tolerance while providing care (Cheng et al., 2016; Peacock et al., 2010). A sense of mastery over

caregiving skills enables caregivers to feel more competent while providing care. Mastery also results in caregivers being able to adapt and to cope better with the challenges of caregiving (Peacock et al., 2010). Reciprocity is another positive aspect of caregiving. Reciprocity means that caregivers are able to give back to other caregivers by sharing their knowledge and experiences and providing comfort to other individuals in similar situations (Cheng et al., 2016). Giving back cultivates a sense of usefulness and purpose. Although caregiving has positive benefits for caregivers, it is important to reiterate that caregivers are at a higher risk of negative physical and mental health outcomes than non-caregivers (Chan et al., 2013; Pinquart & Sörensen, 2003). Accordingly, this literature review will focus on the negative health outcomes of caregiving, specifically depression, in order to gain an understanding of how to improve caregiver health.

Caregiver Depression. Caregiver depression is a negative health outcome requiring attention because it is a predictor of functional decline and poor health status (Covinsky et al., 1997; Shao et al., 2017). Poor physical and mental health can compromise a caregiver's ability to assist his or her family member, which can lead to the provision of poor quality care. Poor quality care refers to caregiver behaviour that can potentially cause psychological or physical harm onto the individual requiring care (Beach et al., 2005). Examples of potentially harmful behaviour include screaming and yelling, threatening to relocate a family member into a nursing home, withholding food, and economic abuse, among others. Studies show that a link exists between depression and potentially harmful behaviour exhibited by the caregiver. Beach and colleagues (2005) found that caregivers who were at-risk for clinical depression were more likely to engage in potentially harmful behaviour. As well, in a longitudinal study on the associations between caregiver stressors, caregiver depression and quality of care, Smith and colleagues (2011) reported that caregivers who were more depressed provided less respectful care and reported more potentially harmful behaviour. Caregivers in the study who reported increases in depressive symptoms also reported more occurrences of potentially harmful behaviours (Smith, Williamson, Miller, & Schulz, 2011). Consequentially, caregiver depression has implications for both the caregiver and for the individual to whom he or she provides care. Depression affects a caregiver's health, which in turn affects his or her ability to provide care. Caregivers' depression impacts the care and quality of life of the individual requiring assistance, increasing the risk of institutionalization for the care-recipient (Czaja et al., 2009).

Predictors of Depressive Symptoms in Caregivers. Depression has an impact on the well-being of the caregiver and the individual to whom she/he provides care. It is important to examine the predictors of depressive symptoms in caregivers in order to understand how to improve caregivers' mental health. Selected demographic characteristics of informal caregivers are predictors of depressive symptoms. Age and gender influence depression risk for caregivers. Younger caregivers and female caregivers report more depressive symptoms compared to older caregivers and male caregivers, respectively (Arai et al., 2014; Luchsinger et al., 2015; Pinquart & Sorensen, 2011; Williams, 2005; Won et al., 2017; Young et al., 2008).

Younger caregivers, such as adult children, may have competing roles and responsibilities for caregiving compared to older caregivers such as spouses (Bastawrous, Gignac, Kapral, & Cameron, 2015; Li et al., 1997; Pearlin et al., 1990; Pinquart & Sorensen, 2011; Skaff & Pearlin, 1992). Adult-children may be caring for their own children while also caring for an aging parent. Adult-children caregivers also are more likely to be employed than spouse caregivers and may be balancing employment with caregiving duties (Pinquart & Sorensen, 2011; Sinha, 2013). Multiple roles in a caregiver's life may limit the time a caregiver has to engage in desired activities, increasing vulnerability to depressive symptoms.

Women's social roles and the role strains they face may contribute to higher rates of depression compared to men. Many women are employed full-time and also are expected to care for their own children and aging parents. Women are more likely to provide more care and assist with personal care tasks compared to men (Sorensen, Duberstein, Gill, & Pinquart, 2006). The responsibilities of multiple role identities can lead to role overload and strain, increasing the risk of depression (Bastawrous et al., 2015; Nolen-Hoeksema, 2001). The gendered differences in social roles and expectations may contribute to depression. Unlike women, men are not socialized to take on more nurturing roles such as caregiving, decreasing the risk of experiencing role overload and developing depressive symptoms. In addition, women are more likely to report depressive symptoms than men (Piccinelli & Wilkinson, 1999; Sorensen, Duberstein, Gill, & Pinquart, 2006). As a result, women may be overrepresented in the depression literature compared to men.

Income and living arrangement are other significant demographic predictors of depressive symptoms. Lower income is associated with higher rates of depressive symptoms (Arai et al., 2014; Cummings & Kropf, 2015; Kim & Lee, 2003; Kim et al., 2011; Miller et al., 2001; Pinquart & Sorensen, 2011; Schulz et al., 1995; Williams, 2005; Won et al., 2017). Income influences an individual's ability to access resources. Caregivers with lower income may be unable to afford access to resources needed to lessen stress and to improve well-being, such as home care, respite care, or counselling services. This may explain why lower income is associated with a higher risk of depression. Caregivers who live with the individual for whom they are caring experience higher amounts of depressive symptoms compared to caregivers who do not co-reside with the individual requiring care (Arai et al., 2014). Caregivers who live with the individual requiring care may experience caregiving stressors more frequently than caregivers who do not co-reside with the individuals for whom they provide care. A caregiver who lives with an ill family member may spend more time providing care and may provide more intensive care compared to a non co-residing caregiver. Caregivers who live with the individual requiring care may have less time for respite and may experience more chronic stress compared to caregivers who do not share a household with the individual for whom they care.

Kinship is another predictor of caregivers' depression. Studies show that spouses are more likely to report higher levels of depressive symptoms than non-spousal caregivers, such as adult-children (Berg-Weger, Rubio, & Tebb, 2000; Cummings & Kropf, 2015; Pinquart & Sorensen, 2011; Schulz et al., 1995; Williams, 2005; Young et al., 2008). The level of depression risk also is influenced by the gender and marital status of the spousal caregiver. Wives are at a greater risk of depression and experience more depressive symptoms compared to husbands (Arai et al., 2014; Bookwala & Schulz, 2000; Cummings & Kropf, 2015; Haley et al., 2003). Caregiver health is another predictor of depressive symptoms. Poor caregiver health and a higher number of health problems are associated with higher depression scores (Arai et al., 2014; Cummings & Kropf, 2015; Haley et al., 2003; Luchsinger et al., 2015; Miller et al., 2001; Piercy et al., 2013; Schulz et al., 1995; Williams, 2005).

Along with demographic characteristics, factors related to caregiving itself can impact caregivers' level of risk for depression. The characteristics of the individual requiring care can influence depressive symptoms in caregivers. These characteristics include the severity of cognitive impairment of the individual requiring care and problem behaviours. Dementia severity impacts depression for caregivers providing care to an individual with dementia. More severe levels of dementia in the individual requiring care are associated with higher amounts of depressive symptoms in caregivers (Arai et al., 2014; Williams, 2005). As well, the dementia type of the individual requiring care influences caregiver depression. Caregivers of individuals living with frontotemporal dementia report significantly higher amounts of depressive symptoms than caregivers of individuals living with Alzheimer's disease (Mioshi, Bristow, Cook, & Hodges, 2009). More behavioural problems, such as agitation or wandering, of the individual for whom the caregiver is caring are associated with higher depression scores (Haley et al., 2003; Kim & Lee, 2003; Miller et al., 2001; Piercy et al., 2013; Romero-Moreno, Márquez-González, Mausbach, & Losada, 2012; Schulz et al., 1995; Williams, 2005).

As well, physical limitations of the individual requiring care impact caregivers' vulnerability to depressive symptoms. Peyrovi and colleagues (2012) investigated the relationship between perceived life changes and depression in caregivers of stroke survivors. Study findings revealed that the functional disability of the stroke survivor predicted caregiver depression. More severe disability of the stroke survivor was

associated with caregivers exhibiting higher levels of depressive symptoms (Peyrovi, Mohammad-Saied, Farahani-Nia, & Hoseini, 2012). Lau and Au (2011) conducted a meta-analysis on the correlates of caregiver distress in caregivers of individuals living with Parkinson's Disease (PD). The review found that the severity of the individual with PD's motor symptoms and level of limitation in activities of daily living (ADL) predicted caregiver distress. More severe motor symptoms and more limitation in ADLs were related to higher levels of caregiver distress (Lau & Au, 2011). Higher levels of caregiver distress increase susceptibility to experiencing depressive symptoms.

Factors specific to caregiving, such as the cognitive and physical limitations of the individual requiring care, can affect how a caregiver appraises his or her caregiving situation. Personal appraisals of the caregiving situation can influence depression. Negative appraisals such as being upset by the problem behaviours of the individual requiring caring, are linked with more depressive symptoms than more positive appraisals (Aggar, Ronaldson, & Cameron, 2010; Williams, 2005). Williams (2005) found that caregivers who reported feeling more bothered by the problem behaviours of their ill family member had more depressive symptoms than those who were less bothered by problem behaviours. Peyrovi and colleagues (2012) determined that positive perceptions of life changes associated with caregiving were related to lower depression scores.

The amount of burden experienced by a caregiver while providing care also can predict depression. Caregiver burden focuses on the impact of the physical, psychological, social and financial demands of caregiving on the caregiver (Pinquart & Sorensen, 2003). Caregivers with higher amounts of burden reported more depressive symptoms compared to caregivers with lower amounts of burden (Schulz et al., 1995; Song, Biegel, & Milligan, 1997; Young et al., 2008). In their study on depression in family caregivers of cancer patients, Young and colleagues (2008) found that caregivers who felt burdened faced a six times greater risk of depression than caregivers who felt less burdened.

Social variables, such as social support and social participation, are other predictors of depressive symptoms in caregivers. The amount of perceived social support plays an important role in predicting depressive symptoms. Lower perceived social support is related to higher levels of depressive symptoms (Kim et al., 2011; Losada et al., 2010). The type of social support a caregiver receives also can influence depression. A study by Miller and colleagues (2001) revealed that lower levels of informal instrumental and emotional support are linked with higher levels of depressive symptoms. Instrumental informal support refers to amount of assistance a caregiver receives from family or friends with tasks such as household chores (Miller et al., 2001). Social network size is another factor associated with depressive symptoms. A larger social network is related to lower amounts of depressive symptoms (Haley et al., 2003; Piercy et al., 2013; Williams, 2005). Social participation also can influence the risk of developing depressive symptoms. Lower levels of social participation are associated with higher depression scores (Croezen et al., 2015; Ghosh & Greenberg, 2012; Li et al., 1997; Loucks-Atkinson et al., 2006; Mausbach et al., 2008). Two aspects of social participation related to caregiver depressive symptomology include the frequency of social participation and perception of leisure time. Wakui and colleagues (2012) found that weekly engagement in home or social activities by Japanese family caregivers was significantly related to lower depression scores. A study on leisure and distress in caregivers of older adults

found that caregivers who perceived they had more leisure time reported lower depression scores (Losada et al., 2010). Engagement in social and leisure activities aids in alleviating the negative psychological health outcomes of caregiving.

The experience of depressive symptoms by caregivers can be influenced by demographic characteristics, stressors related to caregiving, and social variables. Accordingly, it is important to gain a deeper understanding of the caregiving context and the factors that influence depression in caregivers. The caregiving and stress process model is one theoretical construct that can be used to explain why caregivers are susceptible to developing depressive symptoms.

Caregiving and the Stress Process

The caregiving and stress process model (Pearlin et al., 1990) is intended to explain how stress manifests itself in caregivers and how caregiving impacts a caregiver's life. The model, developed by Leonard Pearlin and colleagues, originates from the stress process model (Pearlin, Menaghan, Lieberman, & Mullan, 1981). The stress process model examines how life events, chronic life strains, self-concepts, coping methods and social supports interact and create a process of stress (Pearlin et al., 1981). The authors of the stress process model posit that disruptions in life events result in the creation of new life strains or in the intensification of existing life strains and this produces stress. Life strains lead to decreases in positive self-concepts such as self-esteem or mastery. Decreases in positive self-concepts can make individuals more susceptible to experiencing negative outcomes of stress, such as depression. The caregiving and stress process situates the development and experience of stress within the context of caregiving. The caregiving and stress process also defines caregiving as a chronic stress experience that consists of four components including (1) the background and contexts of the process, (2) stressors, (3) mediating conditions, and (4) the outcomes of stress. The background and contexts of caregiving refer to the personal characteristics of caregivers, the history and the nature of their relationship with the individual to whom they are providing care, the length of caregiving and access to resources, and social supports. These factors affect how stress is experienced (Pearlin et al., 1990). For example, socioeconomic status affects access to support services such as home care. Support services can help decrease caregiving demands and alleviate some caregiver burden. Caregivers who are unable to afford such services may experience more stress because they are unable to access support which can lessen their workload and help caregivers cope with the task demands of caregiving. Understanding the context of caregiving and taking into account factors such as socioeconomic status and social support can provide insight into why some caregivers experience more stress than others.

The caregiving and stress process states that primary and secondary stressors cause caregiver stress. Stressors are defined as problematic conditions, experiences, and activities (Pearlin et al., 1990). Primary stressors arise directly from caregiving itself and are related to the needs of the individual requiring care, as well as the type and intensity of care required to meet those needs (Pearlin et al., 1990). Examples of primary stressors include the diminishing cognitive or physical ability of the individual needing care, and providing an increasing amount of assistance to that individual. An individual's creating stress. Primary stressors mark the onset of the stress process and lead to the development of secondary stressors (Pearlin et al., 1990).

Secondary stressors are related indirectly to the demands of caregiving. Pearlin and colleagues (1990) divide secondary stressors into two categories including role strains and intrapsychic strains. Role strains refer to the competing demands between caregiving and other roles in a caregiver's life. Strain results from situations such as balancing employment with being a caregiver, and conflict with family members regarding care and caregiving responsibilities (Pearlin et al., 1990). Intrapsychic strains focus on ideas and perceptions of the self. This type of strain occurs when there is a barrier to a positive self-concept such as experiencing a decrease in self-esteem. The increasing demands of caregiving, coupled with role strains, lead to the diminishment of positive self-concepts. Diminishing self-concepts make individuals more vulnerable to stress outcomes, such as poor physical health and depressive symptoms (Pearlin et al., 1990).

The model also includes two mediators of stress: social support and coping. Social support refers to assistance from others with caregiving tasks and to the provision of emotional support by friends or relatives. Coping focuses on the behaviours and strategies the caregiver uses to manage and reduce his or her stress, such as adjusting expectations about one's caregiving responsibilities. Mediators play an important in improving caregiver well-being as they can lessen the intensity of stressors and also limit the development of secondary stressors (Pearlin et al., 1990).

Constriction of a Caregiver's Social Life: The Impact on Social Support and Social Participation. The caregiving and stress process can be used to understand how

25

stress manifests itself in caregivers and why caregivers are at-risk of developing depression. One of the contributing stressors to caregiver depression as outlined in the model is the constriction of a caregiver's social life. The constriction can be related to the concept of social support. Social support can be divided into structural and functional support. These two types of support serve different purposes in an individual's life. Structural support refers to the connection and degree of integration one has with a social network. It can be measured by examining the number of social relationships a person has or how integrated an individual is within their social network (Cohen & Wills, 1985). Social participation is a type of structural support because participating in activities such as sport or recreation, or belonging to organizations and clubs contributes to and creates social integration. Social participation refers to participating in social, leisure, recreational, cultural, and spiritual activities in the community and with family. Participating in social activities presents individuals with the opportunity to become involved in their community and to maintain or create new social relationships (World Health Organization, 2007). Social participation can be seen as a way to access functional social supports. Functional support focuses on the purposes interpersonal relationships serve in an individual's life, such as the provision of emotional support, companionship, and affection (Cohen & Willis, 1985).

Social support and social participation have important implications for an individual's health. Low levels of social support and social participation are associated with an increased risk of mortality (Bennett, 2002; Dalgard & Haheim, 1998; Nieminen, Harkanen, Martelin, Borodulin, & Koskinen, 2015; Nyqvist, Pape, Pellfolk, Forsman, & Wahlbeck; 2014). A strong relationship exists between social participation and mortality

risk. Nieminen and colleagues (2015) analyzed the relationships among social support, social participation, trust, and all-cause mortality risk using population-level data from a national health survey administered in Finland. Social participation was the strongest predictor of mortality. Low levels of social participation were associated with higher mortality rates. The mortality rate of individuals with low levels of social participation (Nieminen et al., 2015). Similarly, a meta-analysis by Nyqvist and colleagues (2014) revealed that higher levels of social participation were associated with a decreased risk of mortality. The significant relationship between social participation and mortality remained regardless of age and gender. Low levels of social support and social participation may exacerbate the mortality risk caregivers face already, given that caregiving puts an individual at an increased risk of death (Schulz & Beach, 1999). Therefore, examining how social support and social participation influence caregiver stress and susceptibility to negative health outcomes is crucial.

According to the caregiving and stress process, social support is a mediator of caregiver stress and stress outcomes. One of the ways in which social support mediates against stress is through buffering effects. Social support acts a buffer and protects an individual against negative outcomes such as physical illness or depression. Social support is most beneficial and can protect against negative outcomes during times of stress (Cohen & Willis, 1985). The buffering effects of social support can be related to caregiving as caregiving is characterized by the experience of chronic stress. Studies show social support is associated with a reduction in negative health outcomes in caregivers. Emotional support buffers against depression in wife- and daughter-caregivers who experience medium or high levels of stress (Li et al., 1997). Caregivers with higher perceived social support and more perceived leisure time reported lower levels of burden, and significantly lower depression scores versus caregivers who reported lower levels of perceived social support and leisure time (Losada et al., 2010). Schuz and colleagues (2015) found participation in affiliation groups, such as sports clubs or religious clubs, to be associated with a reduction in anxiety scores. The findings from studies on social support and caregiving demonstrate that caregivers benefit from experiencing both structural and functional forms of social support.

The provision of emotional support to a caregiver can help alleviate negative emotions, such as anxiety, and can also assist the caregiver in appraising his or her situation more positively (Pearlin et al., 1990). For example, reassurance and encouragement from close friends about the support caregivers are providing to their family members can enable caregivers to realize that they are doing well in their role. This realization causes the caregiver to perceive him or herself and his or her situation more positively. However, caregiving also can lead to a perception of diminishing social support. The increasing dependency of the individual requiring care may limit the time a caregiver has to spend with friends and family, decreasing his or her access to social support and leading to feelings of depression (Li et al., 1997; Pearlin et al., 1990).

Caregiving also can constrain caregivers' abilities to engage in social activities. Caregivers may not always be able to access the opportunity for involvement and socialization associated with participating in social activities because of the stresses and demands associated with caregiving. Growing caregiving duties can limit the amount of time a caregiver has to engage in other activities. Limited time for other activities leads to decreased social participation which increases the risk of depression (Croezen et al., 2015; Li et al., 1997; Loucks-Atkinson et al., 2006). It is important to understand how poor social support and low levels of social participation impact depressive symptoms in caregivers. The activity restriction model of depressed affect (Williamson & Shaffer, 2000) provides a framework to guide insight into the relationship between social participation and depression among caregivers.

The Activity Restriction Model of Depressed Affect. Activity restriction (AR) is defined as a decreased ability to engage in desired activities. It is identified in the literature as a mediator of depression (Mausbach et al., 2011; Williamson & Schulz, 1995; Williamson & Schulz, 1992). The AR model of depressed affect takes into consideration the degree to which an individual's normal activities are restricted due to experiencing a major life stressor. Examples of stressors in a caregiving context include increasing caregiver responsibilities, and the change in the nature of the relationship between the caregiver and the individual to whom he or she is providing care (Pearlin et al., 1990). The degree of activity restriction has a large impact on how an individual adjusts psychologically to a stressor. The extent that a stressor decreases an individual's participation in regular activities has an effect on depressive symptoms, with more restriction resulting in poorer mental health outcomes (Williamson & Schaffer, 2000). Activity restriction therefore acts a mediator between a stressor and mental health outcomes.

This mediating relationship was established in a program of research, led by Gail Williamson, who examined activity restriction and depression in different patient populations. Her initial studies examined the effect of activity restriction on pain and symptoms of depression. The first study focused on community-dwelling older adults with various health conditions and found that activity restriction mediated the relationship between pain and symptoms of depression. Higher depression scores were associated with poorer health and more activity restriction (Williamson & Schulz, 1992). Similar findings emerged from studies involving younger and older persons with cancer, limb amputees, and pediatrics chronic pain patients and their caregivers (Williamson, 1998; Williamson & Schulz, 1995; Williamson et al., 1994). The studies all found activity restriction to have an impact on depressive symptoms. Higher amounts of activity restriction were associated with higher depression scores.

The activity restriction model of depressed affect and the caregiving stress process are both useful when investigating the relationships among social support, social participation and depression in caregivers. The AR model provides information on activity restriction as a mediator for depression. However, it does not explain why some caregivers experience decreases in social participation. This information can be inferred from the caregiving and stress process model by examining the primary and secondary stressors experienced by caregivers such as providing increased assistance to the care receiver and role strains. The caregiving and stress process provides the contextual information needed to understand the relationships among social support, social participation and depression in caregivers.

Caregiving and Activity Restriction

The AR model has been applied to caregiving to study the role of activity restriction in influencing rates of depressive symptoms in caregivers. Mausbach and colleagues (2008) examined activity restriction and depression in caregivers to those with Alzheimer's disease compared to non-caregivers. Their study found activity restriction to be a significant mediator in the relationship between being a caregiver and experiencing depressive symptoms. Caregivers reported more activity restriction and had higher depression scores than non-caregivers. Activity restriction accounted for almost 87% of the between-group differences (caregiver vs. non-caregiver) in depressive symptoms. Caregivers in the study with greater levels of activity restriction had higher depression scores compared to caregivers and non-caregivers with lower levels of restriction (Mausbach et al., 2008). These findings highlight that it is the extent to which caregiving reduces a caregiver's ability to participate in regular activities that influences levels of depressive symptoms. However, the sample size of the study was small (n=25) and the comparison groups were unequal. Sixteen caregivers and only nine non-caregivers participated in the study (Mausbach et al., 2008). Unequal samples in the comparison groups can lead to skewed results. The impact of activity restriction on depression scores may have been overestimated because there were more caregivers in the study. Overestimation may have occurred because a larger number of caregivers compared to non-caregivers would have resulted in more caregiver scores being reported than noncaregivers scores. Unequal samples make it difficult to determine how caregivers differ in activity restriction relative to non-caregivers.

Loucks-Atkinson, Kleiber, and Williamson (2006) provide additional support for the applicability of the AR model to caregiving with their three-year longitudinal study on activity restriction in middle age and older caregivers. The study examined restriction in expressive and instrumental activities. Expressive activities include socializing with friends and participating in recreational activities. Instrumental activities were defined in this study as referring to self-care activities, household chores, and going shopping (Loucks-Atkinson et al., 2006). Activity restriction at Time 1 in the study was related to more depressive symptoms. The investigators found that restriction in both expressive and instrumental activities at Time 1 predicted greater depressive symptoms at Time 2 in the study (Loucks-Atkinson et al., 2006). Restriction in both of these domains at Time 1 also was related to lower social support, lower perceived health status, and an increase in physical symptoms such as back pain. Restrictions in expressive and instrumental activities were predictors for more depression, more physical symptoms and lower perceived health status. Instrumental activity restriction also predicted lower perceived social support at Time 2 (Loucks-Atkinson et al., 2006). It is important to note the study did not have a non-caregiving control group. This makes it difficult to generalize the results to the general population and to determine clearly whether being a caregiver impacts the ability to participate in social activities. Interpretation of the results is limited to caregivers only because there is no non-caregiver comparison group. The study also recruited participants through health and social service agencies. This affects generalizability as the individuals seeking aid from these services are often more distressed caregivers (Loucks-Atkinson et al., 2006). Despite the study limitations, the study findings indicate that restrictions in social and household activities have important consequences for a caregiver's mental and physical health.

The Caregiving Factors that Influence Activity Restriction

The Nature of the Relationship between the Caregiving Dyad. The study by Loucks-Atkinson and colleagues (2006) focuses on how activity restriction can impact negatively a caregiver's mental and physical health, and also on caregivers' perceptions of social support. Their study is related to the work of Li, Seltzer and Greenberg (1997) on social support and depressive symptoms in wife- and daughter-caregiver dyads. Li and colleagues conceptualized social support as consisting of three dimensions: social participation, emotional support, and caregiving support. As noted previously, social participation refers to participating in social, leisure, recreational, cultural, and spiritual activities in the community, and with family (World Health Organization, 2007). Emotional support focuses on receiving assurance and respect from persons in an individual's social network and having a person to confide in. Caregiving support refers to assistance the caregiver receives from others with caregiving tasks (Li et al., 1997). Li and colleagues (1997) found differences in how each dimension of social support impacts depression for wives and daughters. Social participation was only a significant predictor of depressive symptoms in daughters, with higher levels of participation associated with fewer depressive symptoms (Li et al., 1997). This relationship held for daughters, regardless of the level of caregiving stress (high, medium, or low) reported. Emotional support for wives was a significant predictor of depression but only when caregiving stress was at medium or high levels, and when the problem behaviours of the husband were at a medium or high levels. This relationship also was significant for daughters but to a lesser extent than for wives (Li et al., 1997).

The Li et al. (1997) study highlights the importance of examining the caregiver's background and the caregiving context in order to understand why different dimensions of social support can have differential impacts on depressive symptoms in family caregivers. Daughter caregivers may be balancing other roles with their caregiver role such as raising children and being employed (i.e., sandwich generation). Participating in social activities may provide daughter caregivers with time away from the stresses and demands of caring for an ill parent. In addition, social participation can be a way for daughters to access social support by interacting with others during their activities. Daughters likely do not spend time with their aging parents in the same way as wives do with their husbands. For example, daughters often have their own spouse with whom they engage in social activities and rely on for support as opposed to seeking this socialization and support from a parent. Wives rely on their spouses for socialization and support. Therefore, caring for an aging parent may not be as disruptive to a daughter's social life compared to a wife's social life.

Social participation did not influence depressive symptoms in wives. The lack of influence on depression may be because participating in social activities may interfere with a wife's caregiving duties. Wives may be required to leave their husbands at home in order to participate in social activities. Leaving her husband unattended or in the care of someone less familiar with his circumstances may create worry and anxiety while away from home, decreasing a wife's desire to engage in activities outside the home. As well, wives may now be participating in activities alone that they used to do with their husbands. This can lead to feelings of loneliness and depression because wives may be reminded of the relationship and interactions they used to have with their husbands before becoming a caregiver (Li et al., 1997). Wives may not perceive social participation to be of any benefit or importance to them, which may explain why social participation was not a predictor of depression in caregiving wives.

Emotional support does influence depressive symptoms in wives. This influence can be attributed to the high saliency of the wife role for a woman later in life. Role

34

saliency refers to how important a role is to an individual's life and identity. Emotional support has more impact on stress that is linked to emotionally salient roles in an individual's life (Li et al., 1997). Wives caring for ill husbands may experience a loss of emotional support from the spousal relationship. Receiving support from and confiding in friends or family can help alleviate some of this loss by creating reciprocity in relationships with loved ones. Emotional support can help reduce some of the stress of caregiving, reducing the risk of depressive symptoms. The daughter role may be less salient to a woman's self-concept, compared to other roles such as being a wife or mother. Daughters turn to their own spouses for emotional support as opposed to relying on a parent to provide that type of support (Li et al., 1997). For most daughter caregivers, the parent-child relationship typically is not based on the need for emotional support. The losses experienced in that relationship differ from the losses in intimacy and emotional reciprocity experienced by wife caregivers. This is why emotional support may have less of a buffering effect on depressive symptoms in daughter caregivers compared to wife caregivers.

Another important aspect of the caregiving context to consider is how the quality of the relationship between the caregiver and the individual he or she is caring for can influence a caregiver's level of social participation. Williamson, Shaffer, and Schulz (1998) investigated whether caregiver activity restriction would mediate the impact of caregiver stress on feelings of resentment and depressed affect in spouse caregivers caring for a spouse living with cancer. The authors found a positive correlation among caregiver activity restriction and caregiver depression and resentment with the severity of the spouse's cancer symptoms. Caregivers caring for individuals with more severe symptoms exhibited higher amounts of restriction, depressed affect, and feelings of resentment. Activity restriction mediated the relationship between spouse symptom severity, depressed affect and resentment (Williamson, Shaffer, & Schulz, 1998).

The mediation noted above varied based on the quality of the relationship between the caregiver and their spouse. Activity restriction mediated the relationship between spouse symptom severity and depressed affect for caregivers in highly communal relationships. Communal relationships are characterized by high levels of feelings of responsibility for each others' needs and well-being. Caregivers in the study with high levels of activity restriction in intimate and affectionate activities experienced more depressed affect. Activity restriction also mediated the relationship between care receiver symptom severity and resentment for caregivers in low communal relationships (Williamson et al., 1998). These caregivers focused on how caregiving responsibilities infringed on their ability to participate in social and personal activities, leading to them to resent their activity restriction. The findings from this study provide insight into how the nature of the relationship between the caregiver and the individual he or she is caring for influences a caregiver's appraisal of his or her caregiving situation. Caregivers in more communal relationships are affected negatively by a reduction in the personal activities they can share with their partner and as a result experience depressive symptoms. In contrast, caregivers in less communal relationships are affected negatively by how caregiving causes them to reduce their participation in social and leisure activities, resulting in feelings of resentment.

The Demands of Caregiving. Along with the relationship between the caregiver and the individual to whom he or she is providing care, other aspects of the caregiving

36

context that can influence social participation and social support include the task and time demands of caregiving. Nieboer, Schulz, Matthew, Scheier, Ornel and Lindenberg (1998) examined changes in spousal caregivers' activity restriction and depression over time. They found that spouses assisting with at least 4 caregiving tasks at Time 2 in their longitudinal study had significantly higher depression levels than those assisting with less than 4 caregiving tasks. The group with at least four caregiving tasks also reported more activity restriction at Time 2 in the study. Analyses revealed activity restriction to be a significant mediator of depression (Nieboer et al., 1998). These findings are similar to the ones by Miller and Montgomery (1990) in their study on limitations in social activities of family caregivers. Individuals who reported more activity restrictions showed more objective and subjective time and task demands. These individuals assisted their family member with more tasks and also perceived caregiving to be taking up more of their time (Miller & Montgomery, 1990). Additionally, in a study on changes in caregiver leisure participation, 56% of caregivers reported lack of time due to caregiving as a reason why they reduced or stopped participating in leisure activities (Dunn & Strain, 2001). Bastawrous and colleagues (2015) investigated the impact of role overload on lifestyle, participation, and family relationships in caregiving daughters. Participants reported reducing participation in leisure activities. Lack of respite and having less time for the activities were reported as reasons for decreased participation. Participants described feeling overwhelmed by the caregiver role as a result of giving up social and leisure activities (Bastawrous et al., 2015). Findings from the studies described above demonstrate that the amount of objective burden experienced by caregivers influences caregivers' ability to participate in social activities. Assisting with more care tasks and

spending more time providing care decreases the amount of time a caregiver has to engage in other roles and activities.

Activity Restriction and Role Engulfment

Activity restriction and its impact on caregiver depression can be related to the concept of role engulfment. Role engulfment refers to a loss of self, which is the result of "a loss of identity that results from engulfment in the caregiver role" (Skaff & Pearlin, 1992, p.657). Engulfment results in an individual having only the caregiver role to compare himself or herself against and to make self-evaluations. Engulfment into the caregiver role is related to the two aspects of the caregiving and stress process discussed earlier in this review including the relationship between the caregiver and the individual to whom he or she is providing care, and the demands of caregiving. The nature of the relationship between the caregiver and the individual he or she is caring for is an important predictor of self-loss. Skaff and Pearlin (1992) found that spousal caregivers reported more self-loss than adult-children caregivers. This finding can be attributed to the saliency of the spouse role compared to the adult-child role. The spousal relationship is characterized by emotional exchange and reciprocity. Caring for an ill spouse can lead to a loss of intimacy and emotional support for the spouse caregiver because the ill spouse may be unable to contribute to the relationship in the same way as they did prior to their illness. This may also cause the spousal caregiver to limit his or her participation in social activities. As mentioned earlier, one of the reasons that spousal caregivers reduce their social participation is because they may now be participating in activities alone that they used to do previously with their spouse (Li et al., 1997). A loss of self occurs because the caregiver role begins to take over the caregiver's identity. Adultchildren are less likely to report self-loss because the child role is less central to their selfconcept. Adult-children are likely to have their own spouses to turn to for emotional support and engage in social activities with. Caregiving, therefore, may not be as disruptive to an adult-child's life compared to a spouse's life.

As well, the demands of caregiving can influence feelings of self-loss. Caregivers with more caregiving demands are more vulnerable to self-loss (Skaff & Pearlin, 1992). Greater vulnerability to self-loss occurs because increased caregiving demands can limit the time a caregiver has for other activities such as employment, socializing with friends, and engaging in leisure activities. An inability to participate in one's normal activities also can lead to a perceived loss of social support because the caregiver may be interacting with family and friends less often. The reduction in participation and interaction with others can lead a caregiver to feel consumed by caregiving, resulting in a loss of identity.

The concept of role engulfment can be used to understand and to explain why activity restriction can have an impact on depressive symptoms in caregivers. Skaff and Pearlin (1992) state that role engulfment leads to self-loss because an individual has fewer sources of feedback from others to evaluate themselves and their behaviour. This idea is based on the identity process model. According to the model, individuals maintain their identity by receiving feedback from others on their actions and behaviours in their social environment. This social feedback is compared to an individual's identity standard, a set of internalized norms about how one should act and behave (Burke, 1991). If the feedback received is consistent with an individual's internalized norms, identity is maintained. However, if a mismatch exists between the social appraisals and an individual's identity standard, distress can occur (Burke, 1991; Montgomery & Kosloski, 2013). Caregivers engulfed in the caregiving role have only that role as their source of feedback and self-evaluation. Caregivers immersed in this role are unable to get feedback from others about how they are coping with caregiving or performing in other roles in their lives (e.g., being a friend or good employee). Caregivers absorbed by the caregiver role base their self-evaluation solely on their caregiving activities. If caregivers perceive they are not performing well as a caregiver, this can lead to distress and to diminished self-concepts, such as self-esteem. Multiple roles in an individual's life can provide some forms of protection against self-loss because of the different sources of feedback the roles provide (Skaff & Pearlin, 1992).

Along with role-engulfment, caregivers' perception about their abilities to participate in social activities can impact their levels of social participation. In a study on the social participation of Australian caregivers of persons with dementia, participants stated that they felt they had fewer choices in when and how to participate in social activities. These participants discussed experiencing a major loss in social participation. Some individuals participated in activities less often while others reported that they had to give up some activities due to caring for a family member with dementia (Nay et al., 2015). Bedini and Guinan (1996) examined female caregivers' sense of entitlement to leisure participation. They found leisure participation to be linked with a caregiver's perception of leisure, how leisure fit in with her role as a caregiver, a desire for leisure and how leisure was prioritized compared to other responsibilities. The authors of the study categorized the women into four groups based on what each participant said about her views on leisure as a caregiver. Repressors, comprised mostly of spousal caregivers, were individuals who expressed that they did not need leisure or suppressed their desire for leisure. Resenters were individuals who expressed a desire for leisure but were unable to access leisure or felt pressured to give up leisure to be a caregiver. Consolidators were women who included the individual they were caring for in their leisure activities. Rechargers consisted of women who were able to make time for leisure and who stated that leisure was how they regained energy for caregiving (Bedini & Guinan, 1996). Findings from both of the studies discussed above demonstrate that a caregiver's perception of his or her ability to be socially involved influences social participation.

How Changes in Caregiving Influence Activity Restriction

While the majority of this literature review focuses on how the activity restriction of caregivers can lead to depressive symptoms, it is important to note how changes to the caregiving role or context can reduce restriction and depression. Mausbach and colleagues (2014) examined how relocation of individuals living with Alzheimer's disease into long-term care impacts caregiver well-being. Relocation into long-term care was associated with a significant decrease in caregiver activity restriction and an increase in feelings of mastery. Decreases in activity restriction and an increase in mastery accounted for substantial reductions in depression in caregivers post-relocation (Mausbach et al., 2014).

The finding by Mausbach and colleagues (2014) is related to the work of Seltzer and Li (2000) on transitions in caregiving. Daughters who relocated a parent into a nursing home during the study had an increase in social participation. As well, wives who exited the caregiving role during the study experienced an increase in social and leisure activity participation. Wives who continued to provide care in their own home continued to experience a decline in social participation (Seltzer & Li, 2000). Relocating loved ones into long-term care or exiting the caregiver role can assist in alleviating the stresses and demands associated with caregiving. These two scenarios can provide caregivers with more time for themselves, enabling them to participate in social and leisure activities, which can act as a buffer against depression.

The provision of respite care is another way to reduce caregiver activity restriction. Respite provides caregivers with a temporary break from caregiving, allowing caregivers to focus on their own needs (Evans, 2013). Respite can be offered in institutions such as nursing homes, in the community, and within the home (Evans, 2013). Respite care in the community is associated frequently with adult day programs. Adult day programs provide social, recreational and therapeutic activities for older adults with a variety of illnesses or chronic conditions outside of the home (Gaugler et al., 2003). Examples of adult day programming include art therapy, gardening, and music. Tretteteig and colleagues (2017) interviewed caregivers of individuals with dementia attending adult day centres. Caregivers stated they had time for rest and relaxation while the individuals for whom they were caring were at the day centre. Caregivers reported using the respite time to participate in activities and spend time with family and friends (Tretteteig, Vatne, & Rokstad, 2017). Employed caregivers expressed that having their family member attend the adult day centre during the work hours helped to ease their worry about their loved ones during the work day (Tretteteig et al., 2017).

The provision of both respite and assistance with caregiving tasks can improve caregiver mental health. Robinson and colleagues (2013) examined differences between caregivers of individuals living with dementia who were users and non-users of community services. Caregivers receiving respite care and assistance were less depressed than caregivers receiving respite only (Robinson, Buckwalter, & Reed, 2013). Assistance with caregiving tasks lessens caregivers' workload while the provision of respite enables caregivers to take a break from caregiving, protecting against the development of depressive symptoms.

Conclusion and Statement of the Problem

The purpose of the literature review was to describe and to discuss the relationships among social support, social participation, and depression in caregivers. Poor social support and low levels of social participation are associated with higher depression scores in caregivers compared to non-caregivers. The factors that influence caregiver social support and participation were presented such as the relationship between the caregiver and the individual to whom he or she is providing care, and the demands of caregiving. Although the literature on caregiving and different dimensions of social support is extensive, little information exists on the relationship between social support, social participation and depression among caregivers in Canada. The majority of the studies discussed in this literature review were conducted in the United States and Europe. More information on the relationships among social support, social participation and depression in Canadian caregivers is needed in order to gain a better understanding of how these social variables influence depression in a Canadian context. Gaining information about these relationships in a Canadian context will help inform how to improve caregiver mental health in Canada. Additionall, y, the sample sizes in the studies reviewed were small. Small sizes in the reviewed studies ranged from 25 participants (Mausbach et al., 2008) to 310 participants (Loucks-Atkinson et al, 2006).

The objective of this thesis is to investigate the relationships among social support, social participation, and depression among caregivers and non-caregivers in Canada using a large, population-based sample (i.e., CLSA database). Informed by Pearlin's stress process model and the AR model, it is hypothesized that:

- lower scores on the variables of social support and social participation will be linked with higher depression scores for both caregivers and non-caregivers.
- 2. caregivers will report lower scores on the variables of social support and social participation and higher on scores of depression compared with non-caregivers.
- 3. the social support and social participation variables will mediate the relationship between caregiver status and depression.

Chapter 3: Method

Canadian Longitudinal Study on Aging

The Canadian Longitudinal Study on Aging (CLSA) is a prospective, longitudinal cohort study that tracks approximately 50,000 Canadians between the ages of 45 and 85 for a period of 20 years. The main goal of the study is to find ways to improve the health of Canadians by gaining an understanding of the aging process and the factors that influence the aging process. The CLSA examines physical, psychological, and social functioning. CLSA researchers recruited participants by resampling from the Canadian Community Health Survey-Healthy Aging and sampling using provincial healthcare registration databases and random digit dialing (Raina, Wolfson, & Kirkland, 2010). Sampling weights were provided to correct for flaws, such as non-response, in the data that might lead to bias and other differences between the sample and reference population.

The 50,000 participants are split into two groups: the Tracking group and the Comprehensive group. The core information set on all participants is collected every three years including variables such as education, health status, and functional ability, among others. The CLSA Tracking group consists of 20,000 participants. Data collected from the CLSA Tracking group includes demographic and lifestyle/behaviour measures, social measures, physical/clinical measures, psychological measures, economic measures, health status measures, and health services use. The CLSA Comprehensive group consists of 30,000 participants. Participants in the Comprehensive group also undergo a physical assessment and provide blood and urine samples. The physical assessment and procurement of the biospecimen samples take place at a designated collection site within 25-50 km of participants' homes. Individuals in the Comprehensive group participate in face-to-face in-home interviews about their diet, medication use, symptoms of chronic disease, and sleep disorders. Data on the CLSA Tracking group is collected using computer-assisted telephone interviews, while data on the CLSA Comprehensive group is collected using the telephone interviews and computer-assisted personal interviews (Raina, Wolfson, & Kirkland, 2010).

Research Design

The current cross-sectional study examined the social support, social participation and depression scores of informal caregivers and non-caregivers. The current study involved secondary data analysis of the CLSA's Wave 1 (Tracking) Telephone Interview Questionnaire. The current study used demographically matched controls to control for confounding. Non-caregivers were used as a control group. Non-caregivers were CLSA participants who reported that they did not provide assistance to another person within the past 12 months. Caregivers were matched with controls (i.e., non-caregivers) based on age, gender and education. Frequency matching was used for gender and education. The gender and education distributions were the same for both groups. Fuzzy matching was used for age. A caregiver was matched with a non-caregiver of the same gender, with same level of education and whose age was within three years of the caregiver's age. The study controlled for perceived physical health, perceived mental health, total household income and total personal income for both groups. Measures from the CLSA include support, social participation and depression.

Inclusion Criteria

Participants included caregivers to a spouse (husband/wife) or parent. Individuals caring for a common-law partner or a mother/father-in-law also were included. Caregivers living in the same household as the care receiver and caregivers providing care to an individual living in another household were included in the current study. The CLSA database did not specify the location (e.g., same city as caregiver) of the household the individual requiring care is living in when the household was different from the caregiver's household. Participants also must have completed the social support, social participation and/or depression questions in the CLSA Wave 1 (Tracking) telephone interview questionnaire.

Exclusion Criteria

Caregivers not caring for a spouse (husband/wife), common-law partner, parent, or father-in-law/mother-in-law were excluded from the study. CLSA participants excluded from the study included those who a) provided assistance to an individual living in a health care institution, b) reported that the care receiver is deceased, c) reported that they did not know the dwelling location of the care receiver, or d) refused to answer the dwelling location of the care receiver question. Caregivers and non-caregivers who did not complete the social support, social participation and/or depression questions in the questionnaire also were excluded from the study.

Measures

Social Support. The CLSA assessed the availability of social support for participants using the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991) (Appendix E). The 19-item survey measures an

individual's perceived availability of functional support. The survey examines five dimensions of functional support: emotional support, informational support, tangible support, positive social interaction, and affectionate support. Emotional support refers to the expression of positive emotions, the ability to understand another individual's feelings and the encouragement of emotional expression. Informational support is defined as providing advice, guidance, information or feedback. Analyses revealed large amounts of overlap among correlations of the emotional support items and informational support items. As a result, the items were combined to create one emotional/informational support scale (Sherborne & Stewart, 1991). Examples of emotional/informational support include having someone from whom you can get good advice concerning a crisis, and having someone who understands your problems. Tangible support is the provision of aid or behavioural assistance. Tangible support survey items include questions such as having someone to take you to the doctor if needed and having someone to help you if you were confined to bed. Positive social interaction refers to the availability of other individuals to engage in fun activities with. Examples of positive social interaction items include having someone to have a good time with and having someone to get together with for relaxation. Affectionate support refers to expressions of love and affection (Sherbourne & Stewart, 1991).

MOS survey respondents were asked to state how often each type of support was available to them, if they needed it. Response choices included: none of the time, a little of the time, some of the time, most of the time, and all of the time. Higher scores indicate higher amounts of perceived social support. The MOS Social Support Survey demonstrates high convergent validity (r= 0.72 or greater) and high internal-consistency

reliability (estimates exceeded the 0.50 standard) for all social support measures (Sherbourne & Stewart, 1991).

The social support availability section (α = 0.95) of the Wave 1 (Tracking) Questionnaire included questions about participants' perceptions of the types of support available to them if needed. Examples of support listed in the questionnaire include assistance with activities of daily living, having someone to listen if one needs to talk, having someone to obtain advice from in a crisis, having someone to take you to the doctor if needed, and having someone who shows you love and affection (Raina et al., 2010).

Social Participation. Social participation was measured as the frequency of participation in 8 community-related activities over the past 12 months (Appendix F). Examples of community-related activities include spending time with family and friends outside the home, church or religious activities, engaging in sports or physical activities with other people, and volunteer or charity work (Raina et al., 2010). The social participation questions were adopted from the 2008-2009 Canadian Community Health Survey-Healthy Aging (CCHS) and the English Longitudinal Study of Ageing (ELSA). The CCHS examines the factors that influence healthy aging in Canadians aged 45 and over (Statistics Canada, 2010). The ELSA is a longitudinal study focused on collecting data related to the biological, psychological and social aspects of aging in a English residents aged 50 and over (Blake, Bridges, Hussey, & Mandalia, 2015). The social participation measure in the CLSA is not a validated measure (Raina et al., 2010). The alpha coefficient for the study sample was 0.63. Response options included at least once a day, at least once a week, at least once a month, at least once a year, or never. Responses

were rated on a 5-point scale, with zero indicating never participating in a communityrelated activity and four indicating daily participation. Higher scores indicate more frequent participation in community-related activities.

Depression. Depression was measured in the CLSA using the short form of the Center for Epidemiological Studies Depression Scale (CESD-10). The CESD-10 is a 10item self-report scale that measures current levels of depressive symptoms (Andersen, Carter, Malmgren, & Patrick, 1994; Radloff, 1977). CLSA participants were asked ten questions about feelings of hopelessness, loneliness, depression, and sleeping issues (Appendix G). Each participant was asked to state how often in the past week he or she experienced the abovementioned feelings. The alpha coefficient for the study sample was 0.77. Response options included all of the time (5-7 days), occasionally (3-4 days), some of the time (1-2 days), and rarely or never (less than 1 day) (Raina et al., 2010). Each item of the measure was rated on a 4-point scale, with zero indicating none of the time and 3 indicating all the time. Scores from each item were totaled to give an overall score. Scores on the scale ranged from 0 to 30. A score of 10 or greater signifies that an individual is at risk of depression. Higher scores indicate higher levels of depressive symptoms (Andersen et al., 1994).

Demographic Information

Caregiver Status. Participants in the Tracking group were identified as caregivers if they answered "yes" to providing assistance to another individual because of a health or physical limitation in the past 12 months during the computer-assisted telephone interview. The flag for the measure 'providing assistance' was used to identify caregivers in the Tracking group dataset. Caregiver status was dummy coded (0= noncaregiver, 1=caregiver).

Age. Participants in the Tracking group were asked two questions about their age. Participants were asked to provide an exact date of birth, and to state their exact age in years when completing the computer-assisted telephone interview for the Wave 1 (Tracking) Telephone Interview Questionnaire (Canadian Longitudinal Study on Aging [CLSA], 2013). Participants were disqualified from the telephone interview if their age was under 45 years or over 85 years.

Gender. Participants were asked to identify whether they were a man or a woman during the computer-assisted telephone interview (CLSA, 2013). Gender was dummy coded (1= female, 2= male).

Education. Participants were asked four questions about their level of education (Appendix B). They were asked (1) to state the highest grade of elementary or high school they completed, (2) if they graduated from high school or not, (3) if they received any other education that could be counted towards a degree, and (4) what was the highest degree, certificate, or diploma they obtained (CLSA, 2013). Highest level of education completed was used as a control for the study. Highest level of education completed was a categorical variable. Each level of education was assigned a number, with levels ranging from 1 to 6. A higher number indicates a higher level of education.

Perceived Health. Participants were asked to describe their physical health based on a single question (Appendix C). Response options included excellent, very good, good, fair, or poor. Each response was assigned a number, with scores ranging from 0 to 4. A lower score indicates poorer physical health (CLSA, 2013). **Perceived Mental Health.** Participants were asked to describe their mental health based on a single question (Appendix C). Response options included excellent, very good, good, fair, or poor. Each response was assigned a number, with scores ranging from 0 to 4. A lower score indicates poorer mental health (CLSA, 2013).

Income. Participants were asked several questions about their income and standard of living (Appendix D). Participants were asked to report total household income, their major sources of household income, their sources for their personal income, and their best estimate of their total personal income (CLSA, 2013). Total household and total personal income were used as controls for the study. Income levels ranged from less than \$20 000 to more than \$150 000. Each income level was assigned a number, with levels ranging from 1 to 5. A higher number indicates a higher income level. CLSA participants who refused to answer the total household and total personal income questions were excluded from the study.

Data Analysis

The current study controled for age, gender, education, general physical health and mental health stati, and income. The independent variable is caregiving status, the dependent variable is depression scores and social support and social participation are the mediating variables.

Analysis of Variance. Analyses of variance (ANOVA) were used to assess differences in the means of the four domains of social support (affectionate support, emotional/informational support, positive social interaction, and tangible support), social participation and depression between caregivers and non-caregivers. Statistical significance was defined as p<0.01.

Path Analysis. Path analysis was used to investigate the relationships among social support, social participation, and depression between caregivers and noncaregivers. Path analysis focuses on measuring relationships between sets of variables. The aim of path analysis is to estimate the significance and size of hypothesized relationships (Kline, 1998). The path analysis was conducted using the PROCESS macro add-on for SPSS. Analyses were conducted using SPSS version 24.0. PROCESS macro uses ordinary least squares regression to estimate direct and indirect effects in mediation models (Hayes, 2012). In models with multiple mediators, the total indirect effect of the mediators and the specific indirect effect of each mediator are estimated (Hayes, 2009). The indirect effect of an independent variable (X) on a dependent variable (Y) through a mediator (M) is the product of the path coefficients of the X to M path and the M to Y path. The indirect effect is equal to the difference between the total effect and direct effect of X on Y. The indirect effect represents the difference between the effect of X on Y when the mediator is controlled for to when the mediator is not controlled (Hayes & Rockwood, 2016).

The following analyses were conducted to test for mediation (Figure 1). Firstly, the path from caregiver status to depression was examined to determine whether being a caregiver impacts depression scores. This path represented the total effect of caregiver status on depression (Hayes, 2009; Hayes & Rockwood, 2016). Secondly, social support and social participation scores were regressed onto caregiver status. Lastly, a multiple regression model was tested, where depression scores were regressed onto both caregiver status and social support and social participation scores to determine whether social support and social participation impact depression scores in Canadians. This model included the direct effect of caregiver status on depression and the indirect effects of caregiver status on depression through the social support and social participation variables (Hayes & Rockwood, 2016; Hayes, 2009). Specific indirect effects were examined to determine if the social support and social participation variables mediated the relationship between caregiver status and depression. A significant indirect effect indicated mediation was present (Hayes, 2009).

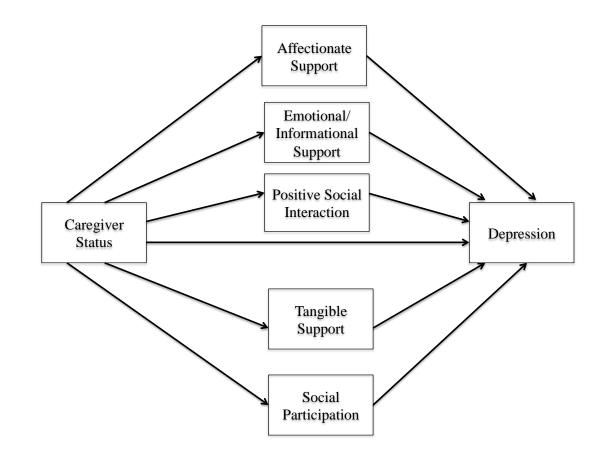


Figure 1. Tested path model

The significance testing approach in the current study differs from the widely used causal steps model for mediation established by Baron and Kenney (1986). The causal steps model tests for mediation in three steps. Firstly, it must be established that the independent variable significantly affects the dependent variable. Secondly, the mediator(s) must significantly affect the dependent variable. Lastly, when the dependent variable is regressed onto both the independent variable and the mediator(s), the previously significant relationship between the independent and dependent variables should no longer be significant (Baron & Kenny, 1986). The decrease in the significance of the relationship between X and Y in the third regression equation indicates that mediation occurred. However, the causal steps approach is one of the lowest power tests for mediation (Hayes, 2009). As well, the approach does not measure the indirect effect of X on Y through M. The presence of an indirect effect is inferred from the regression equations based on hypothesis testing but significance of the indirect effect itself is not tested (Hayes, 2009).

A bootstrap confidence interval is one method that can be used to test for the significance of an indirect effect of X on Y through M. Bootstrapping involves resampling from the current sample. The procedure provides an approximation of the sampling distribution of the indirect effect (Hayes, 2009). Unlike other tests of significance for mediation, such as the Sobel test, bootstrapping is non-parametric. It does not assume the sampling distribution of the indirect effect conforms to a normal distribution (Hayes, 2009). The bootstrap confidence interval is viewed as one of the more powerful and valid methods for testing for indirect effects (Hayes, 2009). A 99% bootstrap confidence interval was calculated for the social support and social participation variables. A significant indirect effect was detected if zero was not within the lower and upper bounds of the confidence interval. As recommended by Hayes (2009), the 99% confidence intervals were based on 5000 bootstrap samples.

Chapter 4: Results

The purpose of this study was to investigate the relationships among social support and social participation on depression in caregivers and non-caregivers using population-level data from the Canadian Longitudinal Study on Aging (CLSA). It was hypothesized that lower levels of social support and social participation would be associated with higher depression scores for both groups. Caregivers were expected to report lower levels of social support and social participation and higher depression scores than non-caregivers. Social support and social participation were predicted to mediate the relationship between caregiver status and depression. Data were analyzed using SPSS version 24.0.

Sample Description

Data from 6,674 CLSA participants were analyzed. Of the total sample, 3,337 participants were non-caregivers and 3,337 participants were caregivers caring for a spouse or parent. Table 1 provides descriptive information for the study participants. Caregivers were matched with non-caregivers based on age, gender, and education. Participant ages ranged from 44 to 87 years, with a mean age of 57 years. Caregivers were slightly older (mean age= 57.13 years) than non-caregivers (mean age= 57.06) years). Table 2 provides information about the means and standard deviations of study variables. Sample weights were applied. Approximately 51% of participants were women and 49% of participants were men. Educational level ranged from having no postsecondary education to having a university degree above a Bachelor's degree. Approximately 46% of participants reported a Bachelor's degree level of education or higher.

The majority of the sample (78%) was married or living with a common-law partner. More caregivers (83%) were married or living with a common-law partner than non-caregivers (72%). Most participants reported perceiving their general health as good (27%), very good (41%), or excellent (21%). Caregivers had slightly better physical health than non-caregivers, with 42% of caregivers rating their health as very good and 22% of caregivers rating their health as excellent. Of the non-caregiver sample, 40% rated their health as very good and 19% rated their health as excellent. Perceived mental health scores were similar to perceived general health scores in both groups. The majority of participants reported perceiving their mental health as very good (38%) or excellent (31%). A higher proportion of caregivers (40%) reported perceiving their mental health as very good than non-caregivers (38%). An equal proportion of participants (31%) from both groups reported their mental health as excellent. Participants were asked to report their total household and total personal income. Approximately 72% of participants reported a total household income of greater than \$50,000. More caregivers (80%) reported total household incomes greater than \$50,000 compared to non-caregivers (72%). Over a third (34%) of participants reported personal incomes of more than \$50,000 but less than \$100,000. A greater proportion of caregivers (50%) reported earning over \$50,000 than non-caregivers (47%).

Variable		Sample 6,674)		aregiver 3,337)	Caregiver (N= 3,337)		
-	$\frac{(N-1)}{N}$	%	$\frac{(N-1)}{N}$	5,557) %	$\frac{(N-1)}{N}$	<u>,,,,,,,,</u> %	
Age							
44-55	2,931	43.9%	1,446	43.3%	1,485	44.5%	
56-65	2,250	33.7%	1,119	33.6%	1,131	33.9%	
56-75	931	14.0%	490	14.6%	441	13.2%	
76-84	535	8.0%	273	8.2%	262	7.9%	
35+	27	0.4%	9	0.3%	18	0.5%	
Gender							
Male	3,284	49.2%	1,642	49.2%	1,642	49.2%	
Female	3,390	50.8%	1,695	50.8%	1,695	50.8%	
Marital Status							
Single, never married, or	529	7.9%	300	9.0%	229	6.9%	
never lived with a							
partner							
Married/living with a	5,170	77.5%	2,388	71.6%	2,782	83.4%	
partner in a common-law							
elationship							
Widowed	272	4.1%	210	6.3%	62	1.9%	
Divorced	520	7.8%	324	9.7%	196	5.9%	
Separated	181	2.7%	115	3.4%	66	2.0%	
Education							
No post-secondary	558	8.4%	279	8.4%	279	8.4%	
legree, certificate, or							
liploma							
Frade certificate or	956	14.5%	478	14.5%	478	14.5%	
liploma from a							
vocational school or							
apprenticeship training			_		_		
Non-university	1,644	24.9%	822	24.9%	822	24.9%	
certificate or diploma							
from a community							
college, CEGEP, etc.							
University certificate	336	5.5%	183	5.5%	183	5.5%	
pelow bachelor's level							
Bachelor's degree	1,902	28.8%	951	28.8%	951	28.8%	

Table 1Description of Sample

University degree or certificate above bachelor's degree	1,178	17.8%	589	17.8%	589	17.8%	
Variable	Entire	Sample	Non-c	aregiver	Caregiver (N= 3,337)		
		5,674)		3,337)			
	N	%	N	%	N	%	
Total household income							
Less than \$20,000	216	3.2%	157	5.0%	59	1.8%	
\$20,000-\$49,999	1,298	19.4%	720	23.0%	578	18.0%	
\$50,000-\$99,999	2,437	36.5%	1 1 1 9	35.7%	1,318	41.1%	
\$100,000-\$149,999	1,366	20.5%	637	20.3%	729	22.8%	
\$150,000 or more	1,023	15.3%	504	16.1%	519	16.2%	
Total personal income							
Less than \$20,000	945	14.2%	517	16.1%	59	1.8%	
\$20,000-\$49,999	2,349	35.2%	1,182	36.8%	578	18.0%	
\$50,000-\$99,999	2,270	34%	1,080	33.6%	1,318	41.1%	
\$100,000-\$149,999	576	8.6%	285	8.9%	729	22.8%	
\$150,000 or more	288	4.3%	149	4.6%	139	4.3%	
Perceived health							
Poor	148	2.2%	104	3.1%	44	1.3%	
Fair	559	8.4%	321	9.6%	238	7.1%	
Good	1,823	27.3%	910	27.3%	913	27.4%	
Very good	2,737	41.0%	1,334	40.0%	1,403	42.1%	
Excellent	1,401	21.0%	664	19.9%	737	22.1%	
Perceived mental health							
Poor	36	0.5%	27	0.8%	9	0.3%	
Fair	305	4.6%	154	4.6%	151	4.5%	
Good	1,618	24.2%	847	25.4%	771	23.1%	
Very good	2,631	39.4%	1,274	38.2%	1,351	40.7%	
Excellent	2,079	31.2%	1,032	31.0%	1,047	31.4%	

			Non-Ca (n= 3	U	Caregory $(n=3)$	
	Min	Max	М	SD	М	SD
Control Variables						
Age (yrs)	44	87	57.06	8.74	57.13	8.62
Perceived health*	0	4	2.69	1.00	2.79	0.91
Perceived mental health	0	4	2.97	0.92	3.00	0.88
Variables of Interest						
Affectionate support*	0	12	10.47	2.39	10.78	1.96
Emotional/informational support*	0	32	26.48	6.08	26.90	5.55
Positive social interaction*	0	16	13.20	3.14	13.43	2.84
Tangible support	0	16	13.21	3.39	13.34	3.04
Social participation*	0	4	2.92	0.65	3.00	0.61
Depression	0	30	5.36	4.82	5.28	4.60

Table 2Means and Standard Deviations by Caregiver Status on Study Variables

Note: Asterisk denotes significant differences in the means between the two groups p<0.01

Assumptions of Linear Regression

Normality. The skewness and kurtosis for the study variables of interest were examined. The assumption of normality was not met. Depression (skew= 1.4, SE= 0.029) was positively skewed, indicating more scores in the lower end of the scale. The distributions for affectionate support (skew= -2.0, SE= 0.028), emotional/informational support (skew= -1.3, SE= 0.029), positive social interaction (skew= -1.3, SE= 0.029), and tangible support (skew= -1.518, SE= 0.029) were negatively skewed. A negative skew indicates more scores in the higher end of the scale. Also, the distribution for social participation (skew= -0.78, SE= 0.029) had a slight negative skew. The distribution for affectionate support (Kurtosis= 4.6, SE=0.057) was leptokurtic. A leptokurtic distribution

indicates that scores are concentrated about the mean, resulting in a more peaked distribution than that of a normal distribution. The distributions for depression (Kurtosis=2.6, SE= 0.057), emotional/informational support (Kurtosis= 2.1, SE= 0.057), positive social interaction (Kurtosis= 1.6, SE= 0.057), tangible support (Kurtosis= 2.5, SE= 0.057), and social participation (Kurtosis= 2.3, SE= 0.057) were slightly platykurtic. A playkurtic distribution indicates that scores are more dispersed resulting in a distribution flatter than that of a normal distribution. The data were not transformed to achieve normality. Transformations were not performed because transforming the data results in changing the variables of interest into different constructs than originally measured, making data interpretation difficult (Grayson, 2004).

Homoscedasticity and Linearity. Scatter plots revealed the assumptions of homoscedasticity and linearity were met.

Multicollinearity. Pearson correlations were performed to examine the relationships between study variables (Table 3). Sample weights were applied. Pearson correlations indicated that no multicollinearity was present.

Table 3	
Pearson Correlations for Study Variables	

Va	riable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10	11.	12.	13.
1.	Depression	-												
2.	Age	037**	-											
3.	Gender	078**	.064**	-										
4.	Education	063**	.021	.012	-									
5.	Perceived health	355**	045**	006	.143**	-								
6.	Perceived mental health	481**	.044**	.021	.102**	.501**	-							
7.	Household income	158**	300**	.075**	.286**	.203**	.131**	-						
8.	Personal income	147**	188**	.269**	.272**	.169**	.128**	.680**	-					
9.	Affectionate support	318**	023*	009	.007	.161**	.214**	.214**	.101**	-				
10.	Emotional/informational	301**	026*	049**	.047**	.168**	.223**	.166**	.091**	.671**	-			
	support													
11.	Positive social interaction	358**	.007	.010	.024**	.179**	.265**	.183**	.110**	.708**	.774**	-		
12.	Tangible support	288**	.022	.079**	.040**	.140**	.193**	.190**	.120**	.643**	.632**	.669**	-	
13.	Social participation	156**	.017	035**	.078**	.157**	.125**	.117**	.064**	.161**	.174**	.206**	.140**	

Note: *p<0.05 **p<0.01

Differences in the Means of Social Support, Social Participation, and Depression

Analysis of variance (ANOVA) was performed to assess differences in means of social support, social participation and depression between caregivers and non-caregivers (Table 2). Significant differences were found in three of the four domains of the Medical Outcomes Study (MOS) Social Support Survey. Caregivers reported higher perceived amounts of affectionate support, emotional/informational support, and positive social interactions versus non-caregivers. The groups did not differ in perceived amounts of tangible support. The means of social participation differed significantly between the two groups. Caregivers participated in community-related activities more frequently than non-caregivers. No significant differences were found in depression scores.

Path Analysis

The SPSS PROCESS macro add-on was used to run the path analysis and test for indirect effects. Table 4 presents the mediation model examining the effect of caregiver status on depression by social support and social participation. Three regression equations were tested. All of the regression equations controlled for age, gender, education, perceived physical health, perceived mental health, and total household and total personal income. Of the total sample, 867 cases were removed from the analysis due to missing data. A total of 5,807 cases were used in the path analysis. The PROCESS macro add-on weighted all cases equally. Unstandardized path coefficients were reported for the analyses discussed below.

The four domains of the MOS Social Support Survey (affectionate support, emotional/informational support, positive social interaction, and tangible support) and social participation were regressed onto caregiver status. This was done to examine the relationship between being a caregiver and levels of social support and social participation. The paths between caregiver status and emotional/ informational support, positive social interaction, and tangible support were not significant. The path between caregiver status and affectionate support was significant (B= 0.18, p=0.001). Being a caregiver versus being a non-caregiver was associated with higher perceived amounts of affectionate support. The path between caregiver status and social participation was significant (B = 0.05, p=0.002). Being a caregiver versus being a non-caregiver was associated with more frequent participation in community-related activities.

Caregiver status was regressed onto depression to determine the total effect of caregiver status on depression (Figure 2). The path between caregiver status and depression was not significant (B=0.17, p=0.031). As discussed by Hayes (2009), a significant relationship between the independent and dependent variables is not required to test for mediation since mediation is focused on the indirect effect of one variable on another.

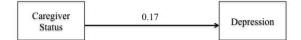


Figure 2. Total effect of caregiver status on depression. Unstandardized path coefficients are reported.

Lastly, caregiver status and the social variables were regressed onto depression (Figure 3). Of the control variables, the paths between gender and depression, perceived health and depression, and perceived mental health and depression were significant. Being a woman was associated with higher amounts of depressive symptoms (B= -0.54, p<0.000). Higher scores on the perceived general health (B= -0.62, p<0.000) and perceived mental health (B= -1.69, p<0.000) scales, indicating better general physical and mental health, were associated with lower depression scores. The paths between affectionate support and depression (B= -0.19, p<0.000), positive social interaction and depression (B = -0.21, p<0.000), and social participation and depression (B = -0.40, p<0.000) were significant. Higher perceived amounts of affectionate support, positive social interaction, and more frequent participation in community-related activities were associated with lower depression scores. The path between caregiver status and depression was not significant. This path represents the direct effect of caregiver status on depression.

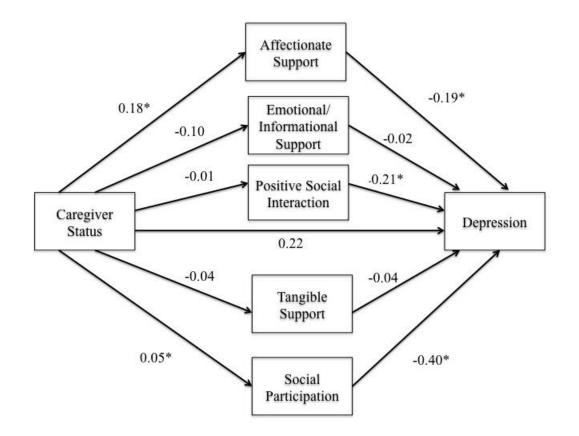


Figure 3. Final path model. Unstandardized path coefficients are reported. *p<0.01.

Bootstrap confidence intervals were used to test for the significance of the indirect effects of caregiver status on depression through the social support and social participation variables. The indirect effect of caregiver status represents the amount by which two cases who differ by 1 unit on X (non-caregiver vs. caregiver) are expected to differ on depression scores through caregiver status's effect on the mediators (social support and social participation) (Hayes, 2009). The *total* indirect effect of caregiver status through the four domains of social support and social participation on depression was not significant. The standardized total indirect effect was -0.0059 (99% CI [-0.016, 0.004]). The specific standardized indirect effects of emotional/informational support, positive social interaction, and tangible support were not significant. The specific indirect

effects of affectionate support and social participation were significant. The standardized indirect effect of affectionate support was -0.0042 (99% CI [-0.0095, -0.001]). The standardized indirect effect of social participation was -0.0025 (99% CI [-0.0058, -0.0006]). Affectionate support and social participation were significant mediators in the relationship between caregiver status and depression. Higher amounts of affectionate support and more frequent participation in community-related activities were related to lower depression scores

Table 4

Mediator variables	Dependent variable Depression	Bootstrap SE
	Path coefficient	
Affectionate support		
Indirect effect	-0.0042*	0.002
Emotional/informational support		
Indirect effect	0.0002	0.001
Positive social interaction		
Indirect effect	0.0004	0.002
Tangible support		
Indirect effect	0.0002	0.001
Social participation		
Indirect effect	-0.0025*	0.001

Mediation Model Examining the Effect of Caregiver Status on Depression by Social Support and Social Participation

Note: Control variables used in the study were age, gender, education, perceived physical health, perceived mental health, and total household and personal income.

The indirect effect refers to the indirect effect of caregiver status on depression through the mediator variables.

*p<0.01

Chapter 5: Discussion

The aim of the present study was to investigate the relationships among social support, social participation, and depression between caregivers and non-caregivers in the CLSA database of Canadian participants. It was hypothesized that (1) lower levels of social support and social participation would be related to higher depression scores, (2) caregivers versus non-caregivers would report lower amounts of social support and social participation and higher depression scores and (3) social support and social participation would mediate the relationship between caregiver status and depression.

The Impact of Social Support on Depression

The path analysis examined the relationships among caregiver status, social support (measured by affectionate support, emotional/informational support, positive social interaction, and tangible support), and depression. Of the four social support domains, affectionate support was the only significant mediator in the relationship between caregiver status and depression. Hypothesis three was supported. Affectionate support refers to verbal and non-verbal expressions of affection (Sherbourne & Stewart, 1991). Examples of affectionate support include words of affirmation, handholding, and hugging. Caregivers and non-caregivers in the sample with higher perceived amounts of affectionate support reported lower depression scores than caregivers and non-caregivers with lower perceived amounts of affectionate support. Hypothesis one was supported.

Affection and affectionate communication have positive impacts on physical and mental health. Research on affection reveals that the receipt of affectionate support is associated with reductions in stress, blood pressure, and depressive symptoms (Floyd, 2014; Hesse & Floyd, 2008). Cohen and colleagues (2015) found that hugging was

associated with a decreased risk of developing an illness. Participants in the study who received hugs more frequently had a lower risk of developing a cold versus participants who were hugged less frequently. As well, more frequent hugging was related with greater amounts of perceived social support (Cohen et al., 2015). Furthermore, research on touch demonstrates that physical touch, such as handholding, is associated with decreases in blood pressure, heart rate, cortisol levels and increases in oxytocin (Field, 2010). Given the positive impact affectionate support has on well-being and the finding from the present study that higher levels of affectionate support are associated with lower depression scores, it is important to examine why affectionate support is beneficial for improving mental health.

Verbal and non-verbal expressions of affection are ways to communicate support to an individual. Research has found that touch is a way to communicate emotions such as love, empathy, reassurance, and gratitude (Field, 2010; Hertenstein et al., 2006). Hertenstein and colleagues (2006) had participants identity the type of emotion being expressed to them based on the type of touch they received on the arm. Participants were able to identify correctly the emotion being conveyed via touch for the majority of the time, including emotions such as love and sympathy. Therefore, affection may be a way to display and provide support to an individual.

The provision of affectionate support to an individual lets the individual know someone is there for him or her and may result in the individual perceiving support is available for him or her, if needed. It may be that individuals in the present study with higher amounts of affectionate support perceived that support was available to them more often, possibly aiding in relieving stress and decreasing vulnerability to depressive

symptoms. This perception of more support could be due to the implicit expression of support via affection. Individuals who received more affectionate support may have viewed the expression of affection as a signal that an individual was there for them to provide encouragement, comfort, and reassurance when needed. Consequently, this perception of support may have created a buffering effect against stress and negative health outcomes such as depression.

Understanding the relationship between affectionate support and depression is particularly beneficial for improving caregiver mental health because caregivers are at an increased risk of depression than non-caregivers (Pinquart & Sorensen, 2003). The mediating effect of affectionate support can be related to the caregiving and stress process model (Pearlin et al., 1990). The creators of the model conceptualize caregiving as a chronic stress experience. It is important to note that caregiving can have a positive impact on a caregiver's life. The positive aspects of caregiving identified by caregivers include developing a closer relationship with the individual requiring care, developing a sense of mastery over caregiving skills, and giving back to other caregivers (Cheng, Mak, Lau, Ng, & Lam, 2016; Li & Loke, 2013; Peacock et al., 2010). However, caregivers are at a higher risk of negative health outcomes than non-caregivers (Pinquart & Sorensen, 2003). Accordingly, it is imperative to gain an understanding of the modifiable factors that can improve caregiver health. The caregiving and stress process model includes mediators of caregiving stress, one of which is social support (Pearlin et al., 1990). Affectionate support is a mediator of stress because it may influence vulnerability to developing negative health outcomes such as depression. It is possible that receiving affectionate support signals to a

caregiver that an individual is there for them to provide comfort and support, helping to mitigate the impact of caregiving stress on the caregiver.

The role of affectionate support in reducing stress is supported by the work of Dietzen and colleagues (2007). The researchers examined the effects of different types of couple interactions on cortisol levels and heart rate responses in women. Women in the study who received a neck or shoulder massage from their partner prior to being exposed to a stressor exhibited significantly lower cortisol levels and heart rate responses to the stressor than women who received verbal social support from their partner or had no social interaction at all with their partner (Ditzen et al., 2007). Furthermore, the receipt of verbal social support alone was not associated with stress reduction (Ditzen et al., 2007). Affectionate touch appears to exert a comforting effect and aids in reducing an individual's stress response (Field, 2010). In addition, Floyd and Riforgiate (2008) found that the receipt of verbal and non-verbal affection from a spouse predicted study participants' waking cortisol levels. Higher amounts of verbal and non-verbal affection predicted higher waking cortisol levels. The Floyd and Riforgiate (2008) study also found that receiving verbal and non-verbal affection more often resulted in a greater decrease in participants' cortisol levels throughout the day. Higher waking cortisol levels and greater decreases in cortisol throughout the day are associated with stress regulation. Dysfunction in the stress regulation response occurs when low waking cortisol levels are present and there is little change in cortisol levels throughout the day (Floyd & Riforgiate, 2008). Therefore, the receipt of affection is associated with aiding in regulating an individual's stress response. Accordingly, individuals in the present study with higher amounts of affectionate support may be receiving the comforting benefits of support on stress more often than individuals

with lower amounts of affectionate support. This may explain why higher amounts of affectionate support are related to lower depression scores.

In addition, affectionate support is linked with an individual feeling loved and wanted (Sherbourne & Stewart, 1991). Feeling loved and wanted may contribute to increases in self-esteem. According to Pearlin and colleagues (1990), decreases in positive self-concepts, such as self-esteem, can increase a caregiver's risk of developing depressive symptoms. Therefore, experiencing an increase in a positive self-concept like self-esteem can potentially reduce the risk of negative health outcomes such as depression. Caregivers in the study with higher amounts of affectionate support also may have experienced increases in self-esteem as a result of the affectionate support. As a result, these caregivers may have reported lower levels of depressive symptoms than caregivers with lower amounts of affectionate support.

Previous research on social support reveals there to be relationship between social support and levels of depressive symptoms. Higher amounts of social support are linked with lower levels of depressive symptoms (Bambara, Turner, Williams, & Haselkorn, 2011; Li et al., 1997; Trivedi et al., 2009). This finding was supported in the present study (hypothesis one). When the paths between social support and depression were examined,, higher perceived amounts of affectionate support and positive social interaction were significantly associated with lower levels of depressive symptoms. However, when the indirect effect of caregiver status on depression via social support was tested, affectionate support was the only domain of the Medical Outcome Study (MOS) Social Support Survey that remained statistically significant.

The significant indirect effect of affectionate support emphasizes the vital role affectionate support may play in improving mental health. The other three domains of the MOS survey (emotional/informational support, positive social interaction, and tangible support) are situation-specific. For example, CLSA participants were asked by interviewers to think about how often emotional support was available to them in times of a crisis, and how often did they have someone to do something enjoyable with. For these social support domains, events such as a crisis or a social activity need to occur for the support to have an impact on an individual. Affectionate support may have a more universal effect on wellbeing. As discussed earlier, the provision of affectionate support may signal to an individual that support is available to him or her. Receiving affectionate support may enable an individual to infer that he or she has someone to turn to when experiencing events such as a personal crisis. Therefore, affectionate support may act as an indicator of the availability of other types of social support.

Differences between Caregivers and Non-Caregivers in Social Support

Caregivers versus non-caregivers reported significantly higher amounts of affectionate support, emotional/informational support, and positive social interaction. Hypothesis two was not supported. Martial status may provide an explanation as to why caregivers versus non-caregivers reported higher levels of social support. A larger proportion of caregivers (83%) were married than non-caregivers (72%). Married individuals in the sample may have been receiving affectionate support more frequently from their spouse compared to non-married individuals because romantic relationships feature more affectionate communication and affectionate touch than platonic relationships (Field, 2010). As well, spouses often live together. As a result, spouses may have more frequent and easier access to support than non-married individuals. This may explain why caregivers had higher levels of social support versus non-caregivers as more caregivers reported being married than non-caregivers. However, the CLSA Tracking (Wave 1) Baseline Questionnaire did not include questions about the quality of interpersonal relationships. Though marital status may be a possible reason why caregivers reported higher amounts of social support versus non-caregivers, definitive conclusions about the relationship between marital status and social support cannot be made.

The Impact of Social Participation on Depression

Social participation was a significant mediator in the relationship between caregiver status and depression. Hypothesis three was supported. Caregivers and noncaregivers who participated more frequently in community-related activities reported lower depression scores versus caregivers and non-caregivers who participated less frequently in community-related activities. This finding supports hypothesis one and provides support for the activity restriction model of depressed affect (Williamson & Schaffer, 2000). The authors of the model posit that it is the extent to which a stressor decreases participation in regular activities, such as socializing with friends or volunteer work, that influences depressive symptoms. Decreased participation is related to higher depression scores. Also, the finding of the impact of social participation on depression supports previous research examining caregiving and social participation (Bookwala & Schulz, 2000; Ghosh & Greenberg, 2012; Loucks-Atkinson et al., 2006; Mausbach et al., 2008).

Social participation refers to participating in social, leisure, recreational, cultural, and spiritual activities in the community and with family, and is a way to create and to maintain social relationships (World Health Organization, 2007). Social participation provides access to functional support. This type of support refers to the different purposes interpersonal relationships serve in a person's life such as the provision of emotional support and affection (Sherbourne & Stewart, 1991). Access to functional support may explain why social participation influenced levels of depressive symptoms in the study sample. Study participants reported how often they participated in community-related activities such as volunteer work, being involved with religious organizations, or recreational sports. Activities such as these enable individuals to form social relationships with others in their community and in turn may provide individuals with access to social support. The majority of caregivers and non-caregivers in the present study reported weekly participation in a community activity. It is possible that weekly participation provides individuals with more frequent contact with others in the community, enabling the formation and maintenance of social relationships. Seeing others in the community more often may provide individuals with the time to establish familiarity and develop comfort in their relationships with others involved in the same activity. For example, participating in a recreational sports league can lead to the formation of friendships with team members. Over time, these friendships could extend beyond the sports team and provide individuals with social support in times of stress and need.

Social participation may influence depressive symptomology in caregivers by aiding in maintaining a caregiver's sense of self. The maintenance of a sense of self can be related to Burke's (1991) identity process theory. Persons in an individual's social environment help maintain an individual's identity by providing him or her with feedback on his or her behaviours. Identity is maintained if the feedback aligns with the individual's norms about how he or she should behave. Distress occurs if there is a mismatch between the social appraisals and the individual's internalized beliefs about how he or she should behave (Burke, 1991; Montgomery & Klososki, 2013).

While caregiving can have a positive impact on a caregiver's life (e.g. feeling closer to the individual needing care and developing mastery over caregiving skills), being a caregiver can result in a loss of self (Skaff & Pearlin, 1990). As caregiving responsibilities increase and care intensifies, caregivers may have less time to participate in social activities. As a result, caregivers may be unable to receive feedback from others about how they are coping with caregiving or performing in other roles in their lives (e.g. being a good friend). Reducing social participation may result in a caregiver basing her/his self-evaluation solely on his or her caregiver role. A caregiver's perception that he or she is performing poorly as a caregiver could lead to distress and decreases in positive self-concepts, such as self-esteem because the caregiver's actions do not match up with his or her internalized beliefs about how he or she should be performing in the caregiver role. Decreases in positive self-concepts increase the risk of developing depressive symptoms (Pearlin et al, 1990; Skaff & Pearlin, 1992; Montgomery & Klososki, 2013).

Accordingly, participating in social activities provides individuals with the opportunity to receive feedback from others on their actions in their social environment and may protect against self-loss. For example, when an individual volunteers for a charitable organization, he or she takes on the role of a volunteer and the responsibilities associated with that role such as assisting with fundraising. The individual is able to

evaluate how he or she is performing in the volunteer role based on the feedback he or she receives from others about his or her performance in the role. The appraisal is partially based on what others think of the individual in his or her role. If the individual perceives he or she is performing well in the volunteer role, he or she may experience increases in self-esteem or mastery. It may be that caregivers in the present study who participated in community-related activities more frequently reported lower depression scores because they were receiving feedback on their actions and behaviours outside of the caregiver role more often than caregivers with less frequent participation. This frequent feedback may aid in reinforcing positive self-concepts, possibly decreasing vulnerability to depressive symptoms.

Differences in Social Participation between Caregivers and Non-Caregivers

Caregivers versus non-caregivers reported significantly higher levels of social participation. Hypothesis two was not supported. The majority of caregivers (69%) and non-caregivers (67%) reported weekly participation in activities. The type of assistance caregivers reported providing may explain why caregivers did not report lower levels of social participation than non-caregivers as predicted. The majority of caregivers reported providing assistance with transportation (81%), activities such as household chores (65%), and meal preparation and delivery (53%). Transportation was the most common type of assistance provided. This finding is similar to the findings on the type of caregiving assistance provided from the 2012 General Social Survey (Sinha, 2013). Assistance with instrumental activities, such as the ones described above, is less intensive and less time-consuming than providing assistance with personal care tasks such as feeding or bathing (National Alliance for Caregiving, 2015; Sinha, 2013). Providing

assistance with personal care tasks requires a caregiver to be available when needed by the individual needing care. This requirement can reduce the time a caregiver has to engage in non-caregiving activities, such as volunteering or socializing with friends. Given that the majority of the caregivers in the present study provided assistance with instrumental activities, they may have had more time to participate in community-related activities. The provision of less intensive care may explain why caregivers reported higher levels of social participation than expected.

In addition, demographic characteristics may explain differences in social participation between caregivers and non-caregivers. Income may be a contributing factor to caregivers' higher social participation levels. Caregivers reported significantly higher total household incomes than non-caregivers. Income provides individuals with the resources and opportunities to engage in social activities. Due to higher total household incomes, caregivers may have had more financial freedom to participate in the social activities examined in the CLSA such as recreational sports, or visiting museums and attending cultural events than non-caregivers. As well, physical health may explain why non-caregivers reported lower social participation scores than expected. A larger proportion of non-caregivers (13%) versus caregivers (8%) reported their physical health as poor or fair. Poor physical health can restrict individuals' abilities to participate in activities in their community (Griffin et al., 2016). For example, a chronic condition such as arthritis can impact an individual's mobility. Mobility limitations may decrease an individual's desire to participate in social activities as he or she may have difficulty with tasks such as walking to a community centre where social programming is offered. Non-

caregivers may have participated in community-related activities less frequently than predicted because more non-caregivers reported poorer physical health versus caregivers.

Differences in Depression between Caregivers and Non-Caregivers

No significant differences were found in depression scores between caregivers versus non-caregivers. Hypothesis two was not supported. The present study included a non-caregiver control group, and all participants (i.e., caregivers and non-caregivers) were from a nationally representative dataset. It may be that caregivers in the present study were not experiencing levels of distress that would significantly influence their levels of depressive symptoms. Several previous studies on caregiving and social support did not use a non-caregiver control group (Loucks-Atkinson et al., 2006; Schuz et al., 2015; Wakui et al., 2012) but rather recruited caregivers from health and social services agencies (Loucks-Atkinson et al., 2006; Wakui et al., 2012). The exclusion of a control group makes it difficult to determine the impact caregiving has on a caregiver's mental health relative to the general population. Recruiting caregivers from health and social services agencies impacts generalizability of study results because caregivers seeking assistance from these services are often more distressed (Loucks-Atkinson et al., 2006). As a result, these caregivers may be exhibiting higher levels of depressive symptoms than caregivers not using support services.

The type of assistance provided by caregivers in the present study may explain why no significant differences were found in depression scores between the two groups. As discussed earlier, the majority of caregivers in the sample were assisting with instrumental activities such as providing transportation. The provision of assistance with instrumental activities is less intensive than, for example, assisting with personal care tasks (National Alliance for Caregiving, 2015; Sinha, 2013). Consequently, caregivers in the present study may not have perceived their caregiving responsibilities to be stressful and distressing. Type of assistance provided and perception of stress related to caregiving duties are possible reasons why depression scores did not differ between caregivers and non-caregivers.

Additionally, the majority of caregivers in the sample were adult-children caring for a parent. Adult-children are more likely to assist with instrumental activities than personal care tasks (National Alliance for Caregiving, 2015). Assistance with instrumental tasks aligns with the role expectations of an adult-child. It is perceived by adult-children that it is part of their role as a child to assist their parents with activities such as household chores and meal preparation (Montgomery & Kosloski, 2013). As this type of assistance aligns with the expectations of the child role, it does not contribute to caregiver distress and the risk of developing depressive symptoms. Distress occurs when caregiving duties do not match role expectations (Montgomery & Kosloski, 2013; Savundranayagam & Montgomery, 2010). For example, an adult-child providing his or her parent assistance with toileting may find this distressing because it is typically not expected for a child to provide this type of assistance to a parent, especially across sex (i.e., son attending to mother's toileting or bathing needs, and daughter attending to father's toileting or bathing needs). It may be that caregivers in the present study were not distressed and therefore not experiencing high levels of depressive symptoms because most caregivers in the sample were adult-children providing assistance on instrumental tasks that aligned with their expectations of their caregiving duties. This may explain why no differences in depression scores were found between caregivers and non-caregivers.

Limitations

Several limitations should be considered when interpreting the findings from the present study. Firstly, the CLSA did not include a measure on caregiver burden. The term caregiver burden refers to the impact of the physical, psychological, social and financial demands of caregiving on the caregiver (Pinquart & Sorensen, 2003) and is a predictor of caregiver depression (Schulz et al., 1995; Song, Biegel, & Milligan, 1997; Young et al., 2008). It was difficult to infer whether caregivers were experiencing depressive symptoms because of stresses associated with caregiving or because of other extraneous factors (e.g., job loss or a death in the family) without a measure of caregiver burden. Secondly, CLSA researchers did not collect information on the health condition of the individual for whom the caregiver was providing care. The health condition of the individual requiring care is a key component in understanding the experience of caregiving and caregiving stress for the caregiver. For example, caregivers of individuals with dementia are more stressed and at greater risk of developing depression than caregivers of individuals with other chronic diseases (Schulz & Martire, 2004). Dementia caregivers are more stressed because the cognitive changes in the individual with dementia require the caregiver to be extremely vigilant when providing care and addressing problem behaviours such as aggression and wandering. Caregiving for people with dementia is more intensive and may impose greater infringement on a caregiver's life than other types of caregiving, increasing vulnerability to experiencing depressive symptoms (Schulz & Martire, 2004). Since CLSA researchers did not record the health condition of the individual requiring care, we were unable to examine how the individual's health condition influenced caregivers' levels of social support and social

participation. Also, we were unable to investigate how the health condition of the individual requiring care influences caregiver depression in Canada. Thirdly, the CLSA did not include a measure on relationship quality. Participants were asked to state their marital status but were not asked any questions about the quality of their interpersonal relationships. As a result, we were unable to examine the relationship between social support and relationship quality. As well, 867 cases were excluded from the path analysis due to missing data. Of the study variables of interest, 44 participants were missing data related to affectionate support, 174 participants were missing data related to emotional/informational support, 69 participants were missing data related to positive social interaction, 116 participants were missing data related to tangible support, 63 participants were missing data related to social participation and 147 participants were missing data related to depression scores. This may have biased the results. Lastly, the present study used cross-sectional data. Therefore, causality cannot be determined definitively and as a result, the direction of the relationships in this study should be interpreted with caution.

Implications

To our knowledge, the present study is the first population-level Canadian study to investigate the relationships among social support, social participation, and depression between caregivers and non-caregivers. The findings provide valuable information on the differences in social support, social participation and depression scores between caregivers versus non-caregivers. The findings also provide insight into how social support and social participation influence depression in Canadians using nationally representative data. The current study revealed that higher amounts of affectionate support and social participation were associated with lower levels of depressive symptoms. Additionally, the present study specified the type of social support that was beneficial to caregivers. Caregiver support strategies must consider the importance of social support and social participation when addressing caregiver mental health.

Implications for Policy. The study findings have important implications for policy. Social participation demonstrated a potential protective effect against depression. More frequent participation in community-related activities was related to lower amounts of depressive symptoms. It is important to ensure that caregivers in Canada are able to participate in desired social activities. One approach to encourage and to support social participation for caregivers is to reduce the amount of objective burden experienced by caregivers. Objective burden refers to the extent to which caregiving imposes on the time a caregiver has for non-caregiving activities such as socializing with friends (Savundranayagam & Montgomery, 2010). One strategy for alleviating objective burden involves ensuring caregivers feel supported in their workplaces.

Workplace support for caregivers is essential given that many Canadians are balancing being employed with caregiving responsibilities (Sinha, 2013). Canadian workplaces should examine implementing flexible workplace arrangements and paid care leave for caregivers. Examples of flexible work arrangements include having the option to work from home or outside the place of employment if needed, allowing employees to start or finish their work day earlier or later than normal, and sharing job positions (Employer Panel for Caregivers, 2015). Paid care leave enables caregivers to take paid time off work to provide care. Flexible work arrangements and paid care leave would assist in reducing objective burden because caregivers would be able to take the time they need to provide care without having to juggle and worry about multiple roles. This may reduce some of the stresses associated with caregiving and provide caregivers with time for participation in social activities. Given the current employment profiles in Canada (i.e., older adults working longer in the workforce; more people engaged in part-time work) there are compelling reasons to take advantage of part-time workers to support those who may want to reduce their work-time or to take a temporary, full-time leave of their job to attend to their caregiver duties. Using part-time workers to fill the workplace roles of caregivers who have either reduced their work hours or taken a care leave from work would bring benefits to employers and would assist in creating a supportive work environment for employees acting as caregivers. Employers would be able to fill positions and maintain productivity while caregivers would be given the time they need to attend to their caregiving responsibilities.

Implications for Practice. Affectionate support plays an important role in reducing vulnerability to depressive symptoms. Given that caregivers benefit from the receipt of affectionate support, caregiver support interventions should include education about the importance of affectionate support. As well, interventions should provide information to family members or friends of caregivers about ways to enhance affectionate support. The inclusion of the family is crucial in ensuring that family members are aware of the impact affectionate support has on caregivers and are informed about how to provide support for the caregiver.

The study findings also have implications for caregiver assessment strategies. Health and social service agencies should assess the caregiver and his or her ability to provide care, and inquire about caregivers' levels and sources of social support and social participation during the in-take process. Conducting a caregiver assessment allows service providers to have baseline information on the factors that influence caregiver health, enabling service providers to track how a caregiver is coping with providing care. Collecting information on caregivers' social support and social participation levels would enable health and social service agencies to intervene when necessary and assist caregivers in accessing and enhancing social support. Early intervention would assist in protecting caregivers against negative mental health outcomes.

The study findings related to social participation and its impact on depressive symptoms have implications for the design of caregiver support groups. As discussed earlier, social participation is a way to access social support. It may to beneficial to create caregiver support groups centred around a social activity, such as a book club or painting. Support groups such as these would allow caregivers to interact with and develop relationships with other caregivers in a more informal way than attending a formal support group. An informal support setting would assist those individuals who feel uncomfortable sharing personal information in a formal support group setting. The social activity support group would enable caregivers to create and foster relationships with one another while gaining the benefits of social participation.

Directions for Future Research

The present study provides support for the roles of affectionate support and social participation as mediators of depression in family caregivers in a Canadian context. Additionally, it identifies the type of social support that is beneficial for Canadian caregivers.

Affectionate support may influence levels of depression in caregivers because affectionate support may be indicator about the availability of other types of social support such as emotional support. Future research should examine if the receipt of affectionate support leads to other types of social support. For example, are individuals who report higher amounts of affectionate support more likely to report higher amounts of emotional/informational support, positive social interaction, and/or tangible support? As well, researchers should investigate whether the source of support plays a role in influencing levels of depressive symptoms. For example, it is more beneficial to receive affectionate support from a spouse/partner versus a relative or friend? Additionally, the majority of the research on affection discussed earlier was conducted in North America. Cultures and religions outside of the Western world may have different beliefs and norms about affection. For example, in the Muslim religion, men and women are not allowed to touch in public. Future studies should investigate how cultural and/or religious beliefs influence the receipt of and perceptions of affectionate support. This is especially important because of the various ethnic and religious groups that reside in Canada.

The present study concluded that more frequent participation in communityrelated activities led to lower depression scores. This finding highlights the vital role social participation plays in improving caregiver mental health. Therefore, it is important to ensure caregivers are able to participate in social activities. Future research should examine how to encourage and facilitate social participation for caregivers. Researchers should examine what are the best strategies to use to encourage caregivers to participate in social activities. Also, future studies should investigate the role the community environment plays in facilitating social participation for caregivers. For example, what are the differences in social participation between caregivers residing in urban centres versus caregivers residing in rural areas in Canada? This type of research is needed given that environment in which one lives can serve as either a barrier or facilitator for social participation. Along with investigating how to facilitate social participation, researchers should determine if certain types of social activities are more beneficial than others for Canadian caregivers. For example, do caregivers involved with volunteer work experience better mental health outcomes than caregivers participating in recreational/leisure activities such as sports? This type of information is central in determining what are the most beneficial ways to improve caregiver support and caregiver mental health in Canada. As well, future research examining the impact of social support and social participation on caregivers should include information about the health condition of the individual requiring care. The inclusion of the health condition of the individual requiring care in future studies would enable researchers to determine how different health conditions and the caregiving duties associated with these conditions influence caregivers' levels of social support and social participation.

Conclusion

The present study examined the relationships among social support, social participation, and depression between caregivers and non-caregivers in Canada. This is the first Canadian study to investigate the relationships between the social variables and depression. The population-level analysis provides insight into how social support and social participation influences depressive symptoms in Canadians. Another unique contribution of the study is that the study identifies the type of social support most beneficial for caregivers. Higher amounts of affectionate support and more frequent participation in community-related activities were associated with lower depression scores. The study findings highlight the important roles affectionate support and social participation play in improving caregiver mental health. Caregiver support strategies and programs must consider the type of social support caregivers are receiving and caregivers' ability to engage in social activities when addressing caregiver mental health.

References

- Aggar, C., Ronaldson, S., & Cameron, I. D. (2010). Reactions to caregiving of frail, older persons predict depression. *International Journal of Mental Health Nursing*, 19, 409–415. http://doi.org/10.1111/j.1447-0349.2010.00688.x
- Alliance for a National Seniors Strategy. (2016). *An evidence-informed national seniors strategy for Canada*. Retrieved from http://www.nationalseniorsstrategy.ca/wpcontent/uploads/2015/01/National-Seniors-Strategy-Second-Edition.pdf
- Andersen, E. M., Carter, W. B., Malmgren, J. A., & Patrick, D. L. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D. American Journal of Preventative Medicine, 10(2), 77–84.
- Arai, Y., Kumamoto, K., Mizuno, Y., & Washio, M. (2014). Depression among family caregivers of community-dwelling older people who used services under the Long Term Care Insurance program: A large-scale population-based study in Japan. *Aging & Mental Health*, 18(1), 81–91. http://doi.org/10.1080/13607863.2013.787045
- Auditor General of Ontario. (2015). 2015 annual report of the office of the Auditor General of Ontario. Retrieved from http://www.auditor.on.ca/en/content/annualreports/arreports/en15/2015AR_en_final. pdf
- Bambara, J. K., Turner, A. P., Williams, R. M., & Haselkorn, J. K. (2011). Perceived social support and depression among Veterans with multiple sclerosis. *Disability* and Rehabilitation, 33(1), 1–8. http://doi.org/10.3109/09638288.2010.481026
- Baron, R., & Kenny, D. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal* of Personality and Social Psychology, 51(6), 1173–1182. http://doi.org/10.1037/0022-3514.51.6.1173
- Beach, S. R., Schulz, R., Wiliamson, G. M., Miller, L. S., Weiner, M. F., & Lance, C. E. (2005). Risk factors for potentially harmful infomal caregiver behavior. *Journal of the American Geriatrics Society*, 53, 255–261.
- Bedini, L., & Guinan, D. (1996). "If I could just be selfish": Caregivers' perceptions of their entitlement to leisure. *Leisure Sciences*, 18, 227–239. Retrieved from http://www.tandfonline.com/doi/full/10.1080/01490409609513284
- Bennett, K. M. (2002). Low level social engagement as a precursor of mortality among people in later life. Age and Ageing, 31(3), 165–168. http://doi.org/10.1093/ageing/31.3.165

- Berg-Weger, M., Rubio, D. M., & Tebb, S. S. (2000). Living with and caring for older family members: Issues related to caregiver well-being. *Journal of Gerontological Social Work*, 33(2), 47–62. http://doi.org/10.1300/J083v33n02_04
- Blake, M., Bridges, S., Hussey, D., & Mandalia, D. (2015). *The dynamics of ageing : The 2010 English Longitudinal Study of Ageing (Wave 5) Technical Report.*
- Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: the Caregiver Health Effects Study. *Psychology and Aging*, 15(4), 607–616. http://doi.org/10.1037/0882-7974.15.4.607
- Burke, P. J. (1991). Identity processes and social stress. *American Sociological Review*, 56(6), 836–849.
- Canadian Caregiver Coalition. (2015). *Care & work : A balancing act.* Retrieved from http://www.internationalcarers.org/wp-content/uploads/2015/08/CCC-Care-and-Work_infographic-web.pdf
- Canadian Institute for Health Information. (2011). Seniors and the health care system : What Is the impact of multiple chronic conditions? Retrieved from https://secure.cihi.ca/free_products/air-chronic_disease_aib_en.pdf
- Canadian Institute for Health Information. (2016). *National Health Expenditure Trends*, 1975 to 2016. Retrieved from https://secure.cihi.ca/free_products/nhex_trends_narrative_report_2016_en.pdf
- Canadian Longitudinal Study on Aging. (2013). 60-min . Questionnaire (Tracking Main Wave + injury) [Measurement instrument].
- Chan, A., Malhotra, C., Malhotra, R., Rush, A. J., & Østbye, T. (2013). Health impacts of caregiving for older adults with functional limitations: results from the Singapore survey on informal caregiving. *Journal of Aging and Health*, 25(6), 998–1012. http://doi.org/10.1177/0898264313494801
- Cheng, S. T., Mak, E. P. M., Lau, R. W. L., Ng, N. S. S., & Lam, L. C. W. (2016). Voices of Alzheimer caregivers on positive aspects of caregiving. *Gerontologist*, 56(3), 451–460. http://doi.org/10.1093/geront/gnu118
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310–357. http://doi.org/10.1037/0033-2909.98.2.310
- Cohen, S., Janicki-Deverts, D., Turner, R. B., & Doyle, W. J. (2015). Does hugging provide stress-buffering social support? A study of susceptibility to upper respiratory infection and illness. *Psychological Science*, 26(2), 135–47. http://doi.org/10.1177/0956797614559284

- Chan, A., Malhotra, C., Malhotra, R., Rush, A. J., & Østbye, T. (2013). Health impacts of caregiving for older adults with functional limitations: results from the Singapore survey on informal caregiving. *Journal of Aging and Health*, 25(6), 998–1012. http://doi.org/10.1177/0898264313494801
- Covinsky, K. E., Fortinsky, R. H., Palmer, R. M., Kresevic, D. M., & Landefeld, C. S. (1997). Relation between symptoms of depression and health staus outcomes in acutely ill hospitalized older persons. *Annals of Internal Medicine*, 126(6), 417–425. http://doi.org/10.1001/jama.1966.03110240153072
- Croezen, S., Avendano, M., Burdorf, A., & Van Lenthe, F. J. (2015). Social participation and depression in old age: A fixed-effects analysis in 10 european countries. *American Journal of Epidemiology*, 182(2), 168–176. http://doi.org/10.1093/aje/kwv015
- Cummings, S. M., & Kropf, N. P. (2015). Predictors of depression among caregivers of older adults with severe mental illness. *Journal of Gerontological Social Work*, 58, 253–71. http://doi.org/10.1080/01634372.2014.978927
- Czaja, S. J., Gitlin, L. N., Schulz, R., Zhang, S., Burgio, L. D., Stevens, A. B., ... Gallagher-Thompson, D. (2009). Development of the risk appraisal measure: A brief screen to identify risk areas and guide interventions for dementia caregivers. *Journal* of the American Geriatrics Society, 57(6), 1064–1072. http://doi.org/10.1111/j.1532-5415.2009.02260.x
- Dalgard, O. S., & Lund Håheim, L. (1998). Psychosocial risk factors and mortality: a prospective study with special focus on social support, social participation, and locus of control in Norway. *Journal of Epidemiology and Community Health*, 52(8), 476–81. http://doi.org/10.11
- Denton, F. T., & Spencer, B. G. (2010). Chronic health conditions: changing prevalence in an aging population and some implications for the delivery of health care services. *Canadian Journal on Aging = La Revue Canadienne Du Vieillissement*, 29(1), 11–21. http://doi.org/10.1017/S0714980809990390
- Ditzen, B., Neumann, I. D., Bodenmann, G., von Dawans, B., Turner, R. A., Ehlert, U., & Heinrichs, M. (2007). Effects of different kinds of couple interaction on cortisol and heart rate responses to stress in women. *Psychoneuroendocrinology*, 32(5), 565– 574. http://doi.org/10.1016/j.psyneuen.2007.03.011
- Dunn, N., & Strain, L. (2001). Caregivers at risk?: Changes in leisure participation. *Journal of Leisure Research*, 33(1), 32–55. Retrieved from http://www.cabdirect.org/abstracts/20013084097.html
- Elmslie, K. (2012). Against the growing burden of disease. *Ottawa: Public Health Agency of Canada, Centre for Chronic Disease Prevention.* Retrieved from

http://www.ccgh-csih.ca/assets/Elmslie.pdf

Employer Panel for Caregivers. (2015). When work and caregiving collide.

- Evans, D. (2013). The provision of health and social care services for older people by respite providers. *Contemporary Nurse*, 45(2), 255–263. Retrieved from http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L3 72146854\nhttp://dx.doi.org/10.5172/conu.2013.45.2.255
- Expert Group on Home and Community Care. (2015). Bringing Care Home.
- Field, T. (2010). Touch for socioemotional and physical well-being: A review. *Developmental Review*, 30(4), 367–383. http://doi.org/10.1016/j.dr.2011.01.001
- Floyd, K. (2014). Relational and health correlates of affection deprivation. Western Journal of Communication, 78(4), 383–403. http://doi.org/10.1080/10570314.2014.927071
- Ghosh, S., & Greenberg, J. S. (2012). Gender difference in caregiving experience and the importance of social participation and marital satisfaction among aging mothers and fathers of adults with schizophrenia. *Social Work in Mental Health*, 10(2), 146–168. http://doi.org/10.1080/15332985.2011.600637
- Grayson, D. (2004). Some myths and legends in quantitative psychology. *Understanding Statistics*, *3*(1), 101–134. http://doi.org/10.1207/s15328031us0302_3.
- Griffith, L. E., Raina, P., Levasseur, M., Sohel, N., Payette, H., Tuokko, H., ... Patterson, C. (2016). Functional disability and social participation restriction associated with chronic conditions in middle-aged and older adults. *Journal of Epidemiology and Community Health*, 1–9. http://doi.org/10.1136/jech-2016-207982
- Haley, W.E., LaMonde, L.A, Han, B., Burton, A.M., & Schonwetter, R. (2003).
 Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. *Journal of Palliative Medicine*, 6(2), 215–224. http://doi.org/10.1089/109662103764978461
- Hayes, A. F. (2009). Beyond Baron and Kenny: Statistical mediation analysis in the new millennium. *Communication Monographs*, 76(4), 408–420. http://doi.org/10.1080/0363775090331036
- Hayes, A. F. (2012). PROCESS: A versatile computational tool for observed variable mediation, mod- eration, and conditional process modeling [White paper]. Retrieved from http://www.afhayes.com/ public/process2012.pdf
- Hayes, A. F., & Rockwood, N. J. (2016). Regression-based statistical mediation and moderation analysis in clinical research: Observations, recommendations, and

implementation. *Behaviour Research and Therapy*, 1-19. http://dx.doi.org/10.1016/j.brat.2016.11.001

- Health Quality Ontario. (2015). *Measuring Up: A yearly report on how Ontario's health system is performing*. Retrieved from http://www.hqontario.ca/portals/0/Documents/pr/measuring-up-2015-en.pdf
- Hesse, C., & Floyd, K. (2008). Affectionate experience mediates the effects of alexithymia on mental health and interpersonal relationships. *Journal of Social & Personal Relationships*, 25(5), 793–810. http://doi.org/10.1177/0265407508096696
- Hertenstein, M. J., Keltner, D., App, B., Bulleit, B. A., & Jaskolka, A. R. (2006). Touch communicates distinct emotions. *Emotion*, 6(3), 528–533. http://doi.org/10.1037/1528-3542.6.3.528
- Ho, J. S., Bordon, J., Wang, V., Ceglowski, J., Kim, D. H., Chattillion, E. A., ...
 Mausbach, B. T. (2013). Reduced activity restriction buffers the relations between chronic stress and sympathetic nervous system activation. *Journals of Gerontology Series B Psychological Sciences and Social Sciences*, 69(3), 408–416. http://doi.org/10.1093/geronb/gbt028
- Hollander, M. J., Liu, G., & Chappell, N. L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, *12*(2), 42–49.
- International Federation on Ageing. (2014). *Connecting the dots: Formal and informal care*. Retrieved from http://www.ifa-fiv.org/wp-content/uploads/2013/08/Connecting-the-Dots-Formal-and-Informal-Care-Senior-Government-Officials-Meeting-10th-June-2014.pdf
- Kim, J.-S., & Lee, E.-H. (2003). Cultural and noncultural predictors of health outcomes in Korean daughter and daughter-in-law caregivers. *Public Health Nursing*, 20(2), 111–119. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12588428
- Kim, Y., Carver, C., Rocha-Lima, C., & Shaffer, K. (2011). Depressive symptoms among caregivers of colorectal cancer patients during the first year since diagnosis: a longitudinal investigation. *Psycho-Oncology*, 22, 362–367. http://doi.org/10.1002/pon.2100
- Kline, R. B. (1998). *Principles and practice of structural equation modeling*. Guilford Press: New York.

- Lau, K.-M., & Au, A. (2011). Correlates of informal caregiver distress in Parkinson's Disease: A meta-analysis. *Clinical Gerontologist*, 34(2), 117–131. http://doi.org/10.1080/07317115.2011.539521
- Li, L. W., Seltzer, M.M., & Greenberg, J. S. (1997). Social support and depressive symptoms: differential patterns in wife and daughter caregivers. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 52B(4), S200– S211. http://doi.org/10.1093/geronb/52B.4.S200
- Li, Q., & Loke, A. Y. (2013). The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research. *Psycho-Oncology*, 22(11), 2399–2407. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed11&NEWS= N&AN=2013677879
- Lin, M., & Lucas, H. C. (2013). Too big to fail : Large samples and the p -value problem. Information Systems Research, 7047(August 2016), 1–12. http://doi.org/http://dx.doi.org/10.1287/isre.2013.0480
- Losada, A., Perez-Penaranda, A., Rodriguez-Sanchez, E., Gomez-Marcos, M. A., Ballesteros-Rios, C., Ramos-Carrera, I. R., ... Garcia-Ortiz, L. (2010). Leisure and distress in caregivers for elderly patients. *Archives of Gerontology and Geriatrics*, 50, 347–350. http://doi.org/10.1016/j.archger.2009.06.001
- Loucks-Atkinson, A., Kleiber, D. A., & Williamson, G. M. (2006). Activity restriction and well- being in middle- aged and older caregivers. *Topics in Geriatric Rehabilitation*, 22(4), 269–282. Retrieved from http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2006/10000/Activity _Restriction_and_Well_Being_in_Middle_Aged.3.aspx
- Luchsinger, J. A., Tipiani, D., Torres-Patiño, G., Silver, S., Eimicke, J. P., Ramirez, M., ... Mittelman, M. (2015). Characteristics and mental health of Hispanic dementia caregivers in New York City. *American Journal of Alzheimer's Disease and Other Dementias*, 30(6), 584–590. http://doi.org/10.1177/1533317514568340
- Mausbach, B. T., Chattillion, E. A., Ho, J., Flynn, L. M., Tiznado, D., von Känel, R., ... Grant, I. (2014). Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychology and Aging*, 29(4), 776–786. http://doi.org/10.1037/a0037626
- Mausbach, B. T., Patterson, T. L., & Grant, I. (2008). Is depression in Alzheimer's caregivers really due to activity restriction? A preliminary mediational test of the activity restriction model. *Journal of Behavior Therapy and Experimental Psychiatry*, 39, 459–466. http://doi.org/10.1016/j.jbtep.2007.12.001
- Miller, B., & Montgomery, A. (1990). Family caregivers and limitations in social

activities. Research on Aging, 12(1), 72–93.

- Miller, B., Townsend, A., Carpenter, E., Montgomery, R. V, Stull, D., & Young, R. F. (2001). Social support and caregiver distress: a replication analysis. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 56B(4), S249– S256. http://doi.org/10.1093/geronb/56.4.S249
- Mioshi, E., Bristow, M., Cook, R., & Hodges, J. R. (2009). Factors underlying caregiver stress in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 27(1), 76–81. http://doi.org/10.1159/000193626
- Montgomery, R. J. V., Kosloski, R.D. (2013). Pathways to a caregiver identity and implications for support services. In R. C. Talley & R. J. V. Montgomery (Eds.), *Caregiving across the lifespan: Research, practice, policy* (pp. 131–156). New York: Springer Science + Business Media.
- National Alliance for Caregiving. (2015). *Caregiving in the U.S. 2015*. Retrieved from http://www.caregiving.org/wpcontent/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

National Institute on Aging. (2007). Why population aging matters: A global perspective.

- Nay, R., Bauer, M., Fetherstonhaugh, D., Moyle, W., Tarzia, L., & McAuliffe, L. (2015). Social participation and family carers of people living with dementia in Australia. *Health and Social Care in the Community*, 23(5), 550–558. http://doi.org/10.1111/hsc.12163
- Nieboer, A. P., Schulz, R., Matthews, K. A., Scheier, M. F., Ormel, J., & Lindenberg, S. M. (1998). Spousal caregivers' activity restriction and depression: A model for changes over time. *Social Science and Medicine*, 47(9), 1361–1371.
- Nieminen, T., Härkänen, T., Martelin, T., Borodulin, K., & Koskinen, S. (2015). Social capital and all-cause mortality among Finnish men and women aged 30-79. *European Journal of Public Health*, 25(6), 972–978. http://doi.org/10.1093/eurpub/ckv058
- Nolen-Hoeksema, S. (2001). Gender differences in depression. *Psychological Science*, *10*(5), 173–176. http://doi.org/10.3109/09540261.2010.492391
- Nyqvist, F., Pape, B., Pellfolk, T., Forsman, A. K., & Wahlbeck, K. (2014). Structural and cognitive aspects of social Capital and all-cause mortality: A meta-analysis of cohort studies. *Social Indicators Research*, 116(2), 545–566. http://doi.org/10.1007/s11205-013-0288-9
- Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., ... Henderson, S. R. (2010). The positive aspects of the caregiving journey with

dementia: using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology*, 29(5), 640–659. http://doi.org/10.1177/0733464809341471

- Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social Behavior*, 22(4), 337–356.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594. http://doi.org/10.1093/geront/30.5.583
- Peyrovi, H., Mohammad-Saeid, D., Farahani-Nia, M., & Hoseini, F. (2012). The relationship between perceived life changes and depression in caregivers of stroke patients. *Journal of Neuroscience Nursing*, 44(6), 329–336.
- Piccinelli, M., & Wilkinson, G. (1999). Gender differences in depression. *British Journal* of Psychiatry, 177, 486–493. http://doi.org/10.1192/bjp.177.6.486
- Piercy, K. W., Fauth, E. B., Norton, M. C., Pfister, R., Corcoran, C. D., Rabins, P. V., ... Tschanz, J. T. (2013). Predictors of dementia caregiver depressive symptoms in a population: The Cache County dementia progression study. *Journals of Gerontology* - *Series B Psychological Sciences and Social Sciences*, 68(6), 921–926. http://doi.org/10.1093/geronb/gbs116
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, 18(2), 250–267. http://doi.org/10.1037/0882-7974.18.2.250
- Pinquart, M., & Sorensen, S. (2011). Spouses, adult children and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26(1), 1–14. http://doi.org/10.1037/a0021863
- Preacher, K., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behaviour Research Methods, Instruments, & Computers*, 36(4), 717–731. http://doi.org/10.3758/BF03206553
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385–401. http://doi.org/10.1177/014662167700100306
- Raina, Wolfson, & Kirkland. (2010). *Canadian Longitudinal Study on Aging (CLSA) protocol.*
- Romero-Moreno, R., Márquez-González, M., Mausbach, B. T., & Losada, A. (2012). Variables modulating depression in dementia caregivers: a longitudinal study. *International Psychogeriatrics*, 24(8), 1316–1324. http://doi.org/10.1017/S1041610211002237

- Savundranayagam, M. Y., & Montgomery, R. J. V. (2010). Impact of role discrepancies on caregiver burden among spouses. *Research on Aging*, 32(2), 175–199. http://doi.org/10.1177/0164027509351473
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalance, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240–9. http://doi.org/10.1176/appi.ajgp.12.3.240
- Schulz, R., Obrien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving - Prevalence, correlates, and causes. *The Gerontologist*, 35(6), 771–791. http://doi.org/10.1093/geront/35.6.771
- Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving : Transitions during a three-year prospective study. *The Gerontologist*, 40(2), 165–178.
- Shao, H., Mohammed, M. U., Thomas, N., Babazadeh, S., Yang, S., Shi, Q., & Shi, L. (2017). Evaluating excessive burden of depression on health status and health care utilization among patients With hypertension in a nationally representative sample from the medial expenditure panel survey (MEPS 2012). *The Journal of Nervous and Mental Disease*, 205(5), 397–404. http://doi.org/10.1097/NMD.000000000000618
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. Social Science and Medicine. http://doi.org/10.1016/0277-9536(91)90150-B
- Sinha, M. (2013). *Portrait of caregivers*, 2012. Retrieved from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm
- Skaff, M. M., & Pearlin, L. I. (1992). Caregiving : Role engulfment and the loss of self. *The Gerontologist*, 32(5), 656–664.
- Smith, R., Williamson, G. M., Miller, L. S., & Schulz, R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychology* and Aging, 26(3), 584–591. http://doi.org/10.1037/a0022263
- Song, L. Y., Biegel, D. E., & Milligan, S. E. (1997). Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community Mental Health Journal*, 33(4), 269–86. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9250425
- Sorensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurology*, 5(11), 961–973. http://doi.org/10.1016/S1474-4422(06)70599-3

Statistics Canada. (2010). Canadian community health survey (CCHS) - Healthy aging

[measurement instrument]. Retrieved from

http://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item_Id= 53430&UL=1

- Statistics Canada. (2011). *Generations in Canada: Age and sex, 2011 census*. Retrieved from http://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.pdf
- Statistics Canada. (2015). *Canada's population estimates: Age and sex, July 1, 2015*. Retrieved from http://www.statcan.gc.ca/daily-quotidien/150929/dq150929beng.htm
- Statistics Canada. (2017). Age and sex, and type of dwelling data: Key results from the 2016 Census. Retrieved from http://www.statcan.gc.ca/dailyquotidien/170503/dq170503a-eng.pdf
- Szklo, M. (1998). Population-based cohort studies. *Epidemiologic Reviews*, 20(1), 81–90. http://doi.org/10.1093/oxfordjournals.epirev.a017974
- Taylor, G. (2014). *The Chief Public Health Officer's report on the state of public health in Canada 2014 - public health in the future*. Retrieved from http://www.phacaspc.gc.ca/cphorsphc-respcacsp/2014/assets/pdf/2014-eng.pdf
- Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2017). The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *BMC Geriatrics*, 17(5), 1–11. http://doi.org/10.1080/13607863.2015.1023765
- Trivedi, R. B., Blumenthal, J. A., O'Connor, C., Adams, K., Hinderliter, A., Dupree, C., ... Sherwood, A. (2009). Coping styles in heart failure patients with depressive symptoms. *Journal of Psychosomatic Research*, 67(4), 339–346. http://doi.org/10.1016/j.jpsychores.2009.05.014
- Turcotte, M. (2013). *Family caregiving: What are the consequences*? Retrieved from http://www.statcan.gc.ca/access_acces/alternative_alternatif.action?l=eng&loc=/pub /75-006-x/2013001/article/11858-eng.pdf

Turner, A., & Findlay, L. (2012). Informal caregiving for seniors.

- Wakui, T., Saito, T., Agree, E. M., & Kai, I. (2012). Effects of home, outside leisure, social, and peer activity on psychological health among Japanese family caregivers. *Aging & Mental Health*, 16(4), 500–506. http://doi.org/10.1080/13607863.2011.644263
- Williams, I. C. (2005). Emotional health of black and white dementia caregivers: a contextual examination. *Journal of Gerontology: Psychological Sciences*, 60B(6),

P287–P295. http://doi.org/10.1093/geronb/60.6.P287

- Williamson, G. M., & Schulz, R. (1992). Physical illness and symptoms of depression among elderly outpatients. *Psychology and Aging*, 7(3), 343–351. http://doi.org/10.1037//0882-7974.7.3.343
- Williamson, G. M., & Schulz, R. (1995). Activity restriction mediates the association between pain and depressed affect: a study of younger and older adult cancer patients. *Psychology and Aging*, 10(3), 369–78. http://doi.org/10.1037/0882-7974.10.3.369
- Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology*, 17(2), 152–162. http://doi.org/10.1037/0278-6133.17.2.152
- Williamson, G.M. & Shaffer, D.R. (2000). The activity restriction model of depressed affect. In Williamson G.M, Schaffer, D.R., & Parmalee P, (Eds). *Physical illness* and depression in older adults. A Handbook of Theory, Research and Practice (pp. 173-200). New York: Kluwer Academic / Plenum Publishers.
- Won, M. R., Ahn, M. S., & Choi, Y. J. (2016). Factors associated with perceived depression of Korean adults: Secondary data from the Korean Community Health Survey. *Community Mental Health Journal*, 53(3), 1–9. http://doi.org/10.1007/s10597-016-0035-1
- World Health Organization. (2007). *Global age-friendly cities: A guide*. Retrieved from http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English. pdf
- Young, S. R., Young, H. Y., Park, S., Dong, O. S., Kwang, M. L., Han, J. Y., ... Nam, S. K. (2008). Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. *Journal of Clinical Oncology*, 26(36), 5890–5895. http://doi.org/10.1200/JCO.2007.15.3957

Appendices

Appendix A: Ethics Approval Form

	r: Dr. Marie Savundranayagam ttion: Health Sciences,Western University	
Review Type: Delegat HSREB File Number Study Title: Social Pa Health Perspective		ada: A Population
HSREB Initial Appro HSREB Expiry Date:	oval Date: March 16, 2016 March 16, 2017	
Documents Approved	and/or Received for Information:	
Document Name	Comments	Version Date
Instruments	Instruments - CLSA Tracking Telephone Questionnaire	2014/07/28
monumento	(original is attached; we are not permitted to amend it)	
Western University Protocol The Western University approved the above HSREB approval f		viewed and above. d above,
Western University Protocol The Western University approved the above HSREB approval f conditional to time The Western Unive Ethical Conduct fo Harmonization of Guideline for Good Information Protec Health Canada Mee	ersity Health Science Research Ethics Board (HSREB) has rev e named study, as of the HSREB Initial Approval Date noted a or this study remains valid until the HSREB Expiry Date note ly submission and acceptance of HSREB Continuing Ethics R ersity HSREB operates in compliance with the Tri-Council Po r Research Involving Humans (TCPS2), the International Con Fechnical Requirements for Registration of Pharmaceuticals fo d Clinical Practice Practices (ICH E6 R1), the Ontario Persona tion Act (PHIPA, 2004), Part 4 of the Natural Health Product dical Device Regulations and Part C, Division 5, of the Food a	above. d above, teview. licy Statement aference on or Human Use al Health Regulations,
Western University Protocol The Western University approved the above HSREB approval ff conditional to time The Western Unive Ethical Conduct fo Harmonization of Guideline for Good Information Protee Health Canada Mer Regulations of Heal	ersity Health Science Research Ethics Board (HSREB) has rev e named study, as of the HSREB Initial Approval Date noted a or this study remains valid until the HSREB Expiry Date note ly submission and acceptance of HSREB Continuing Ethics R ersity HSREB operates in compliance with the Tri-Council Po r Research Involving Humans (TCPS2), the International Con Fechnical Requirements for Registration of Pharmaceuticals fo d Clinical Practice Practices (ICH E6 R1), the Ontario Persona tion Act (PHIPA, 2004), Part 4 of the Natural Health Product dical Device Regulations and Part C, Division 5, of the Food a	viewed and above, ed above, teview. dicy Statement ofference on or Human Use al Health Regulations, and Drug
Western University Protocol The Western University approved the above HSREB approval ff conditional to time The Western Unive Ethical Conduct fo Harmonization of Guideline for Good Information Protee Health Canada Mee Regulations of Heat Members of the HS discussions related	ersity Health Science Research Ethics Board (HSREB) has reve e named study, as of the HSREB Initial Approval Date noted a for this study remains valid until the HSREB Expiry Date noted by submission and acceptance of HSREB Continuing Ethics R ersity HSREB operates in compliance with the Tri-Council Po- r Research Involving Humans (TCPS2), the International Con Fechnical Requirements for Registration of Pharmaceuticals for a Clinical Practice Practices (ICH E6 R1), the Ontario Persona tion Act (PHIPA, 2004), Part 4 of the Natural Health Product dical Device Regulations and Part C, Division 5, of the Food a lth Canada. SREB who are named as Investigators in research studies do n to, nor vote on such studies when they are presented to the RI istered with the U.S. Department of Health & Human Services	viewed and above, ed above, teview. dicy Statement ofference on or Human Use al Health Regulations, and Drug ot participate in EB.

Western University, Research, Support Services Bldg., Rm. 5150 London, ON, Canada N6G IG9 t. 519.661.3036 f. 519.850.2466 www.uwo.ca/research/ethics

		ain Wave 60-min. (Tracking v4.0, 2014 Jul 29
Education (I	ED)	
ED_1 ED_ELHS_TRM		
N	/hat is the highest grade of elementary or high school you NLY ONE RESPONSE	have ever completed? COD
	Grade 8 or lower (Québec: Secondary II or lower)	
	Grade 9 - 10 (Québec: Secondary III or IV;	
	Newfoundland and Labrador; 1 st year of Seconda	ry)2
	Grade 11 - 13 (Québec: Secondary V; Newfoundlar	nd
	and Labrador: 2 nd to 4 th year of Secondary)	3
	[DO NOT READ] Don't know/No answer	8
	[DO NOT READ] Refused	9
ED 2		
ED_HSGR_TRM	SK IF ED_1/ED_ELHS_TRM=3] Did you graduate from h	igh school (secondary
S	chool)?	
	Yes1	
	No2	
	[DO NOT READ] Don't know/No answer8	
ED 3	[DO NOT READ] Don't know/No answer8	
ED_3 ED_OTED_TRM	[DO NOT READ] Don't know/No answer8 [DO NOT READ] Refused9	
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer8	counted towards a degree
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	-
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END SKIP TO ED_END
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END SKIP TO ED_END SKIP TO ED_END
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END SKIP TO ED_END
ED_OTED_TRM H	[DO NOT READ] Don't know/No answer	CONTINUE SKIP TO ED_END SKIP TO ED_END SKIP TO ED_END



ED_4 ED_HIGH_TRM What is the highest degree, certificate, or diploma you have obtained? NECESSARY, CODE ONLY ONE RESPONSE	READ LIST IF
No post-secondary degree, certificate, or diploma	01
Trade certificate or diploma from a vocational school or	
apprenticeship training	02
Non-university certificate or diploma from a community college,	
CEGEP, school of nursing, etc.	03
University certificate below bachelor's level	04
Bachelor's degree	05
University degree or certificate above bachelor's degree	06
ED_HIGH_OTSP_TRM Other (please specify:))	97
[DO NOT READ] Don't know/No answer	98
[DO NOT READ] Refused	99

ED_END

102

Page 15 of 189

Appendix C: CLSA General Health Measure



Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

General Health (GEN)

Next I am going to ask you some general questions about your health. By health, we mean not only the absence of disease or injury but also physical, mental, and social well-being.

GEN_1

GEN_HLTH_TRM

In general, would you say your health is excellent, very good, good, fair, or poor? CODE ONLY ONE RESPONSE

Excellent1
Very good2
Good3
Fair4
Poor5
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

GEN_2

GEN_MNTL_TRM

In general, would you say your mental health is excellent, very good, good, fair, or poor? CODE ONLY ONE RESPONSE

Excellent1
Very good2
Good3
Fair4
Poor5
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

Page 38 of 189

Appendix D: CLSA Income Measure



Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

Income (INC)

This next section is about your standard of living. A person's standard of living has been shown to have a relationship to their health. For this reason it is important that we have some understanding of the level of income that you and your family live on. As with all of the other information that you have shared, these answers are kept strictly confidential.

Household Income

INC_1

Thinking about the total income for all <u>household</u> members, from which of the following sources did your household receive any income in the past 12 months? **READ LIST**, **MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, 98 OR 99 ARE SELECTED)**, **CODE ALL THAT APPLY**

INC_SRCE_WG_TRM	Wages and salaries	01
INC_SRCE_SE_TRM	Income from self-employment	02
INC_SRCE_IN_TRM	Dividends and interest (e.g., on bonds, savings)	03
INC_SRCE_EI_TRM	Employment insurance	04
INC_SRCE_CM_TRM	Worker's compensation	05
INC_SRCE_BN_TRM	Benefits from Canada or Quebec Pension Plan	06
INC_SRCE_PN_TRM	Job related retirement pensions, superannuation and annuities	07
INC_SRCE_GV_TRM	RRSP/RRIF (Registered Retirement Savings Plan/Registered	
	Retirement Income Fund)	08
INC_SRCE_OLD_TRM	Old Age Security	09
INC_SRCE_GIS_TRM	Guaranteed Income Supplement	10
INC_SRCE_WF_TRM	Provincial or municipal social assistance or welfare	11
INC_SRCE_CH_TRM	Child Tax Benefit	12
INC_SRCE_SP_TRM	Child support	13
INC_SRCE_AL_TRM	Alimony	14
INC_SRCE_CP_TRM	Capital gains (e.g. profits from sale of stocks)	15
INC_SRCE_NONE_TRM	[DO NOT READ] None	96
INC_SRCE_OT_TRM	Other (e.g., rental income, veterans' pensions)	97
INC_SRCE_DK_NA_TRM	[DO NOT READ] Don't know/No answer	98
INC_SRCE_REFUSED_TRM	[DO NOT READ] Refused	99

Page 185 of 189

clsa élcv		Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28
INC_2	INC_ [OMI major REAI	CONLY IF MORE THAN ONE SOURCE OF INCOME IDENTIFIED AT INC_1/ SRCE_WG_TRM] Of the sources of income you have identified, what are the three T "THREE" IF ONLY TWO SOURCES LISTED AT INC_1/INC_SRCE_WG_TRM] r sources of your <u>household</u> income, starting with the highest source of income? D LIST, IF NECESSARY; CATI PROGRAMMING NOTE: RECALL ONLY THOSE RCES OF INCOME IDENTIFIED AT INC_1/INC_SRCE_WG_TRM
INC_FRST_	TRM	SPECIFY HIGHEST SOURCE OF HOUSEHOLD
	TOM	
INC_SCND_		[ONLY IF INC_1/INC_SRCE_WG_TRM≥2 RESPONSES] SPECIFY SECOND HIGHEST SOURCE OF HOUSEHOLD INCOME
INC THRD	TRM	[ONLY IF INC 1/INC SRCE WG TRM≥3 RESPONSES] SPECIFY THIRD

INC_3 INC_TOT_TRM

What is your best estimate of the total household income received by all household members, from all sources, before taxes and deductions, in the past 12 months? Was it...READ LIST, CODE ONLY ONE RESPONSE

Less than \$20,0001	
\$20,000 or more, but less than \$50,0002	
\$50,000 or more, but less than \$100,0003	
\$100,000 or more, but less than \$150,0004	
\$150,000 or more5	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

Page 186 of 189

clsa élcv

Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

Personal Income

INC_4 Thinking about your total <u>personal</u> income, from which of the following sources did you receive any income in the past 12 months? **READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY**

INC_PSRCE_WG_TRM	Wages and salaries	01
INC_PSRCE_SE_TRM	Income from self-employment	02
INC_PSRCE_IN_TRM	Dividends and interest (e.g., on bonds, savings)	03
INC_PSRCE_EI_TRM	Employment insurance	04
INC_PSRCE_CM_TRM	Worker's compensation	05
INC_PSRCE_BN_TRM	Benefits from Canada or Quebec Pension Plan	06
INC_PSRCE_PN_TRM	Job related retirement pensions, superannuation and annuities	07
INC_PSRCE_GV_TRM	RRSP/RRIF (Registered Retirement Savings Plan/Registered	
	Retirement Income Fund)	08
INC_PSRCE_OLD_TRM	Old Age Security	09
INC_PSRCE_GIS_TRM	Guaranteed Income Supplement	10
INC_PSRCE_WF_TRM	Provincial or municipal social assistance or welfare	11
INC_PSRCE_CH_TRM	Child Tax Benefit	12
INC_PSRCE_SP_TRM	Child support	13
INC_PSRCE_AL_TRM	Alimony	14
INC_PSRCE_CP_TRM	Capital gains (e.g. profits from sale of stocks)	15
INC_PSRCE_NONE_TRM	[DO NOT READ] None	96
INC_PSRCE_OT_TRM	Other (e.g., rental income, veterans' pensions)	97
INC_PSRCE_DK_NA_TRM	[DO NOT READ] Don't know/No answer	98
INC_PSRCE_REFUSED_TRM	[DO NOT READ] Refused	99

Page 187 of 189

cisa élcv	Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28
INC_5	[ASK ONLY IF MORE THAN ONE SOURCE OF INCOME IDENTIFIED AT INC_4

C_5 [ASK ONLY IF MORE THAN ONE SOURCE OF INCOME IDENTIFIED AT INC_4/ INC_PSRCE_WG_TRM] Of the sources of income you have identified, what are the three [OMIT "THREE" IF ONLY TWO SOURCES LISTED IN INC_4/ INC_PSRCE_WG_TRM] major sources of personal income, starting with the highest source of income? READ LIST, IF NECESSARY; CATI PROGRAMMING NOTE: RECALL ONLY THOSE SOURCES IDENTIFIED AT INC_4/INC_PSRCE_WG_TRM

INC_PFRST_TRM	SPECIFY HIGHEST SOURCE OF PERSONAL
	INCOME:
INC_PSCND_TRM	[ONLY IF INC_4/INC_PSRCE_WG_TRM≥2 RESPONSES] SPECIFY SECOND
	HIGHEST SOURCE OF PERSONAL INCOME
INC_PTHRD_TRM	[ONLY IF INC_4/INC_PSRCE_WG_TRM≥3 RESPONSES] SPECIFY THIRD
	HIGHEST SOURCE OF PERSONAL INCOME

INC_6

INC_PTOT_TRM

What is your best estimate of your total personal income from all sources, before taxes and deductions, in the past 12 months? Was it...READ LIST, CODE ONLY ONE RESPONSE. INTERVIEWER NOTE: IF INC_6/INC_PTOT_TRM >INC_3/INC_TOT_TRM, THEN ASK: THIS QUESTION ASKS YOU FOR YOUR TOTAL *PERSONAL* INCOME, BUT YOU REPORTED THAT YOUR TOTAL *HOUSEHOLD* INCOME IS LESS THAN YOUR TOTAL PERSONAL INCOME. WHAT IS YOUR TOTAL HOUSEHOLD INCOME AND WHAT IS YOUR TOTAL PERSONAL INCOME? INTERVIEWER: CORRECT RESPONSES AS NECESSARY.

Less than \$20,000	1
\$20,000 or more, but less than \$50,000	2
\$50,000 or more, but less than \$100,000	3
\$100,000 or more, but less than \$150,000	4
\$150,000 or more	5
[DO NOT READ] Don't know/No answer	8
[DO NOT READ] Refused	9

INC_END

Page 188 of 189

Appendix E: CLSA Social Support Availability Measure



Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

Social Support – Availability (SSA)

Next are some questions about the support that is available to you.

People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it? **READ LIST OF STATEMENTS**, CODE ONLY ONE RESPONSE PER STATEMENT

SSA_1 SSA_CONFBED_TRM

Someone to help you if you were confined to bed?

None of the time	.1
A little of the time	.2
Some of the time	.3
Most of the time	.4
All of the time	.5
[DO NOT READ] Don't know/No answer	. 8
[DO NOT READ] Refused	.9

SSA_2

SSA_NDTLK_TRM

Someone you can count on to listen to you when you need to talk?

None of the time1
A little of the time2
Some of the time3
Most of the time4
All of the time5
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

Page 114 of 189



SSA_3

SSA_CRISIS_TRM Someone to give you advice about a crisis?

None of the time1	
A little of the time2	
Some of the time3	
Most of the time4	
All of the time5	
DO NOT READ] Don't know/No answer8	
DO NOT READ] Refused9	

SSA_4 SSA_TYTDR_TRM

Someone to take you to the doctor if needed?

None of the time1	
A little of the time2	
Some of the time3	
Nost of the time4	
All of the time5	
DO NOT READ] Don't know/No answer8	
DO NOT READ] Refused	

SSA_5 SSA_SHLOV_TRM Someone who shows you love and affection?

None of the time1	
A little of the time2	
Some of the time	
Most of the time4	
All of the time5	
[DO NOT READ] Don't know/No answer	
[DO NOT READ] Refused	

Page 115 of 189



SSA_6 SSA_GOODT_TRM

Someone to have a good time with?

None of the time1
A little of the time2
Some of the time
Most of the time4
All of the time5
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

SSA_7 SSA_INFO_TRM

Someone to give you information in order to help you?

None of the time	1
A little of the time	2
Some of the time	3
Most of the time	4
All of the time	5
DO NOT READ] Don't know/No answer	3
DO NOT READ] Refused	9

SSA_8 SSA_CONFID_TRM

Someone to confide in or talk to about yourself or your problems?

None of the time1	1
A little of the time	2
Some of the time	3
Most of the time	4
All of the time	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused	9

Page 116 of 189



SSA_9 SSA_HUGS_TRM

Someone who hugs you?

lone of the time1	
little of the time2	
Some of the time3	
Nost of the time4	
II of the time5	
DO NOT READ] Don't know/No answer8	
DO NOT READ] Refused9	
DO NOT READ] Don't know/No answer8	

SSA_10 SSA_RELAX_TRM

Someone to get together with for relaxation?

None of the time1
A little of the time2
Some of the time
Most of the time4
All of the time5
[DO NOT READ] Don't know/No answer
[DO NOT READ] Refused

SSA_11 SSA_MEALS_TRM

Someone to prepare your meals if you were unable to do it yourself?

None of the time1	
A little of the time2	
Some of the time3	
Most of the time4	
All of the time5	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

Page 117 of 189



SSA_12 SSA_ADVCE_TRM

Someone whose advice you really want?

None of the time1	
A little of the time2	
Some of the time3	
Most of the time4	
All of the time5	
DO NOT READ] Don't know/No answer8	
DO NOT READ] Refused9	

SSA_13 SSA_MINDOFF_TRM

Someone to do things with to help you get your mind off things?

None of the time	1
A little of the time	2
Some of the time	3
Most of the time	4
All of the time	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused	Э

SSA_14

SSA_CHORES_TRM Someone to help with daily chores if you were sick?

None of the time1
A little of the time2
Some of the time
Most of the time4
All of the time5
[DO NOT READ] Don't know/No answer
[DO NOT READ] Refused9

Page 118 of 189



SSA_15

SSA_SHFEAR_TRM Someone to share your most private worries and fears with?

None of the time1	
A little of the time2	
Some of the time3	
Most of the time4	
All of the time5	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

SSA_16 SSA_SUGG_TRM

Someone to turn to for suggestions about how to deal with a personal problem?

None of the time	1
A little of the time	2
Some of the time	3
Most of the time	4
All of the time	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused	Э

SSA_17

SSA_17 SSA_ENJOY_TRM Someone to do something enjoyable with?

None of the time1
A little of the time2
Some of the time
Most of the time4
All of the time5
[DO NOT READ] Don't know/No answer
[DO NOT READ] Refused9

Page 119 of 189



SSA_18

SSA_PROBLM_TRM Someone who understands your problems?

None of the time1	
A little of the time2	
Some of the time3	
Most of the time4	
All of the time5	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

SSA_19

SSA_LOVU_TRM

Someone to love you and make you feel wanted?

None of the time1	
A little of the time2	2
Some of the time3	\$
Most of the time4	ŀ
All of the time5	;
[DO NOT READ] Don't know/No answer8	\$
[DO NOT READ] Refused9	,

SSA_20 SSA_PET_TRM

Do you have a household pet that provides you with companionship?

Yes1	
No2	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

SSA_END

Page 120 of 189

Appendix F: CLSA Social Participation Measure



Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

Social Participation (SPA)

Now some questions about your social activities.

SPA_1

Which of these statements apply to you? READ EACH STATEMENT, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY

SPA_SOAC_RNP_TRM	l read a daily newspaper01
SPA_SOAC_HY_TRM	I have a hobby or pastime02
SPA_SOAC_HIC_TRM	I have taken a holiday in Canada in the last 12 months03
SPA_SOAC_HOC_TRM	I have taken a holiday outside of Canada in the last 12 months04
SPA_SOAC_DT_TRM	I have gone on a daytrip or outing in the last 12 months05
SPA_SOAC_INT_TRM	I use the internet and/or e-mail06
SPA_SOAC_VOT_TRM	l voted in the last federal, provincial, or municipal election07
SPA_SOAC_NONE_TRM	None of these statements apply to me08
SPA_SOAC_DK_NA_TRM	[DO NOT READ] Don't know/No answer
SPA_SOAC_REFUSED_TRM	[DO NOT READ] Refused

Community-related Activities

The next questions are about community-related activities that you may have participated in during the past 12 months.

In the past 12 months, how often did you participate in…READ LIST OF ACTIVITIES, CODE ONLY ONE RESPONSE PER ACTIVITY

SPA_2

SPA_OUTS_TRM

Family or friendship based activities outside the household? READ IF NECESSARY – examples include: formal and informal activities such as small get-togethers, meals outside of the household, weddings, or reunions

At least once a day	1
At least once a week	2
At least once a month	3
At least once a year	4
Never	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused	9

Page 121 of 189



SPA_3 SPA_CHRCH_TRM

Church or religious activities such as services, committees or choirs

At least once a day1	
At least once a week2	
At least once a month3	
At least once a year4	
Never5	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

SPA_4

SPA_SPORT_TRM

Sports or physical activities that you do with other people

At least once a day1	
At least once a week2	2
At least once a month3	\$
At least once a year4	ŀ
Never	,
[DO NOT READ] Don't know/No answer8	\$
[DO NOT READ] Refused9	,

SPA_5 SPA_EDUC_TRM

Educational and cultural activities involving other people such as attending courses, concerts, plays, or visiting museums

At least once a day1	
At least once a week2	Į.
At least once a month3	
At least once a year4	i.
Never5	
[DO NOT READ] Don't know/No answer8	i.
[DO NOT READ] Refused9	l



SPA_6

SPA_o SPA_CLUB_TRM Service club or fraternal organization activities **READ IF NECESSARY** – Examples include: Lion's Club, Rotary, Kiwanis Club, Royal Canadian Legion, or Foresters

At least once a day1
At least once a week2
At least once a month3
At least once a year4
Never5
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

SPA_7

SPA_NEIBR_TRM

Neighbourhood, community or professional association activities

At least once a day1	e.
At least once a week2	2
At least once a month	3
At least once a year4	ł
Never	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused)

SPA_8

SPA_VOLUN_TRM Volunteer or charity work

At least once a day	1
At least once a week	2
At least once a month	3
At least once a year	4
Never	5
[DO NOT READ] Don't know/No answer	8
[DO NOT READ] Refused	9

Page 123 of 189



SPA_9 SPA_OTACT_TRM

Any other recreational activities involving other people, including hobbies, gardening, poker, bridge, cards, and other games

At least once a day1	L
At least once a week2	2
At least once a month	3
At least once a year	ł
Never	5
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused)

SPA_10

SPA_MORAC_TRM

In the past 12 months, have you felt like you wanted to participate in more social, recreational, or group activities?

Yes1	CONTINUE
No2	SKIP TO SPA_END
[DO NOT READ] Don't know/No answer8	SKIP TO SPA_END
[DO NOT READ] Refused9	SKIP TO SPA_END

Page 124 of 189

clsa élcv

Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

SPA_11

What prevented you from participating in more social, recreational, or group activities? DO NOT READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY

SPA_PREVAC_CO_TRM	Cost01
SPA_PREVAC_TP_TRM	Transportation problems02
SPA_PREVAC_ANA_TRM	Activities not available in the area03
SPA_PREVAC_LNA_TRM	Location not physically accessible04
SPA_PREVAC_TF_TRM	Location is too far05
SPA_PREVAC_HC_TRM	Health condition/limitation06
SPA_PREVAC_TI_TRM	Time of the activities not suitable07
SPA_PREVAC_GA_TRM	Don't want to go alone08
SPA_PREVAC_PR_TRM	Personal or family responsibilities09
SPA_PREVAC_LRR_TRM	Language related reasons10
SPA_PREVAC_TB_TRM	Too busy11
SPA_PREVAC_AF_TRM	Afraid or concerns about safety12
SPA_PREVAC_OT_TRM	Other97
SPA_PREVAC_OTSP_TRM	Other (please specify:)*
SPA_PREVAC_DK_NA_TRM	[DO NOT READ] Don't know/No answer98
SPA_PREVAC_REFUSED_TRM	[DO NOT READ] Refused

*Additional categories coded; refer to data dictionary.

SPA_END

Appendix G: CLSA Depression Measure



Main Wave 60-min. (Tracking) v4.0, 2014 Jul 28

Depression (DEP)

For the next few questions, please think about how you have felt in the past week, that is from [INSERT DATE OF ONE WEEK AGO] to yesterday. I will first read you a question and then I will read you the answers from which you may choose. Please choose the answer that most applies to how you have felt over the past week.

DEP_1

DEP_BOTR_TRM

A

How often were you bothered by things that usually don't bother you? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	
Occasionally (3-4 days)2	
Some of the time (1-2 days)3	
Rarely or never (less than 1 day)4	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

DEP_2

DEP_MIND_TRM

How often did you have trouble keeping your mind on what you were doing? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	
Occasionally (3-4 days)2	
Some of the time (1-2 days)3	
Rarely or never (less than 1 day)4	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

DEP_3 DEP_FLDP_TRM

How often did you feel depressed? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	
Occasionally (3-4 days)2	
Some of the time (1-2 days)3	
Rarely or never (less than 1 day)4	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

Page 96 of 189



DEP_4

DEP_FFRT_TRM

How often did you feel that everything you did was an effort? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	ĺ.
Occasionally (3-4 days)2	2
Some of the time (1-2 days)	3
Rarely or never (less than 1 day)4	ŧ
[DO NOT READ] Don't know/No answer8	3
[DO NOT READ] Refused)

DEP_5

DEP_HPFL_TRM

How often did you feel hopeful about the future? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)	.1
Occasionally (3-4 days)	.2
Some of the time (1-2 days)	.3
Rarely or never (less than 1 day)	.4
[DO NOT READ] Don't know/No answer	.8
[DO NOT READ] Refused	.9

Remember, we are asking about how you have felt in the past week.

DEP_6 DEP_FRFL_TRM

How often did you feel fearful or tearful? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)	1
Occasionally (3-4 days)	2
Some of the time (1-2 days)	3
Rarely or never (less than 1 day)	4
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused	Э



DEP_7 DEP_RSTLS_TRM

How often was your sleep restless? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	
Occasionally (3-4 days)2	
Some of the time (1-2 days)3	
Rarely or never (less than 1 day)4	
[DO NOT READ] Don't know/No answer8	
[DO NOT READ] Refused9	

DEP_8

DEP_HAPP_TRM How often were you happy? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)1	1
Occasionally (3-4 days)2	2
Some of the time (1-2 days)	3
Rarely or never (less than 1 day)	4
[DO NOT READ] Don't know/No answer	3
[DO NOT READ] Refused)

DEP_9 DEP_LONLY_TRM

How often did you feel lonely? READ LIST, CODE ONLY ONE RESPONSE

All of the time (5-7days)	1
Occasionally (3-4 days)	2
Some of the time (1-2 days)	3
Rarely or never (less than 1 day)	4
[DO NOT READ] Don't know/No answer	8
[DO NOT READ] Refused	9

Page 98 of 189



DEP_10 DEP_GTGO_TRM How often did you feel that you could not "get going"? **READ LIST, CODE ONLY ONE RESPONSE**

All of the time (5-7days)1
Occasionally (3-4 days)2
Some of the time (1-2 days)3
Rarely or never (less than 1 day)4
[DO NOT READ] Don't know/No answer8
[DO NOT READ] Refused9

DEP_END

Page 99 of 189

Curriculum Vitae: Jovana Sibalija

Education

Ca	ndidate for Master of Science, Health and Rehabilitation Sciences, Wester	ern University	2017
•	Concentration: Health and Aging		
٠	Thesis: Social support, social participation, and depression among caregiver. Canada: A population health perspective	s and non-caregive:	rs in
Ho	nors Bachelor of Health Sciences, Western University		2015
•	Graduated with distinction		
Re	esearch Experience		
M	aster's Thesis, Western University	September 2015-P	resent
•	Supervisor: Dr. Marie Savundranayagam		
•	Title: Social Support, Social Participation, and Depression among Caregive in Canada: A Population Health Perspective	rs and Non-Careg	ivers
•	 Investigated the relationship among social support availability, social participation, and depression between family caregivers and non-caregivers using population-level data from the Canadian Longitudinal Study on Aging 		sion
Re	search Assistant, Ontario Physiotherapy Association (OPA)	June 2015-Augus	t 2015

- Summarized a report on the future direction of rehabilitative care in Ontario and created a guide explaining all the relevant information for physiotherapists in the report for OPA members
- Interviewed 100 OPA members to obtain feedback on the association's annual conference and created a report for the Board of Directors identifying and explaining key findings from the member interviews
- Conducted an environmental scan of the social media practices of healthcare organizations in Canada and provided recommendations on how the OPA could increase its social media presence and online engagement with the public

Independent Study, Western University

January 2015-April 2015

- Supervisor: Dr. Marie Savundranayagam
- Title: Resident Reactions to Person-Centered Communication by Long-Term Care Staff
- Examined resident reactions in response to conversations involving person-centered communication and missed opportunities for such communication by staff during routine care tasks

Gerontology in Practice, Western University

September 2014-December 2014

• Supervisors: Dr. Aleksandra Zecevic and Dr. John Trevithick

- Title: Potential Implications of Mail Delivery on Older Adults' Risk of Falls in the Winter
- Conducted a scoping literature review using grey and academic literature to determine the potential
 implications of the Canada Post conversion from home delivery of mail to community mailbox
 delivery on older adults' risk of falls in the winter

Democracy and Leadership Lab, Western University October 2012-April 2013

Conducted research in both English and French related to public leadership and democracy in the developing world

Teaching Experience

Teaching Assistant, Health Issues in Aging, Western University January 2016-April 2017

- Led and facilitated tutorial discussions for 72 students on various topics related to health and aging, such as aging stereotypes, family caregiving, and mental health during the Winter 2016 and Winter 2017 semesters
- Marked all assignments promptly and provided detailed feedback to students on the strengths of their assignments, and where and how improvements could be made
- Held individual meetings with students to address student concerns regarding class assignments and course material

Publications

Savundranayagam, M.Y., **Sibalija**, J., & Scotchmer, E. (2016). Resident reactions to person-centered communication by long-term care staff. *American Journal of Alzheimer's Disease & Other Dementias*, *31*(6), 530-537.

Sibalija, J., Ciminksy, M.L., Fuchigami, K., He, M.H., Chen, Y., Trevithick, J., Bickerton, G., & Zecevic, A. (2016). Potential implications of mail delivery conversion on older adults' risk of falls in the winter. *WURJ: Health and Natural Sciences*, 8(1).

Presentations

Sibalija, J., Savundranayagam, M.Y., Orange, JB., & Kloseck, M. (2017, July). *Social support, social participation, and depression among caregivers and non-caregivers in Canada* Poster session presented at 21st International Association of Gerontology and Geriatrics world congress. San Francisco, CA.

Sibalija, J., Savundranayagam, M.Y., Orange, JB., & Kloseck, M. (2017, March). *The impact of social support and social participation on depression in Canadian family caregivers*. Poster session presented at London Health Research Day. London, ON.

Page 2

Sibalija, J., Savundranayagam, M.Y., Orange, JB., & Kloseck, M. (2017, February). *The impact of social support and social participation on depression in Canadian family caregivers*. Poster session presented at the Health and Rehabilitation Sciences Graduate Research Conference. Western University, London, ON.

Sibalija, J., Savundranayagam, M.Y., Orange, JB., & Kloseck, M. (2016, October). *The impact of social support and social participation on depression in Canadian family caregivers*. Poster session presented at the 45th annual scientific and educational meeting of the Canadian Association on Gerontology. Montreal, QC.

Sibalija, J., Ciminksy, M.L., Fuchigami, K., He, M.H., Chen, Y., Trevithick, J., Bickerton, G., & Zecevic, A. (2015, April). *How will the conversion to community mailboxes influence seniors' risk of falls in the winter?* Poster session presented at the 34th annual conference of the Ontario Gerontology Association. Toronto, ON.

Savundranayagam, M.Y., **Sibalija**, J., & Scotchmer, E. (2015, March). *Resident reactions to personcentered communication by long-term care staff.* Poster presentation at the Faculty of Health Sciences Research Day. Western University, London, ON.

Awards & Distinctions

٠	Western Graduate Research Scholarship	2015-2017
•	Queen Elizabeth II Aiming for the Top Tuition Scholarship	2011-2015
٠	Dean's List	2011-2015
٠	Western Scholarship of Distinction: Entrance Scholarship (87% grade 12 average)	2011

Volunteer Experience

٠	Media relations, Health & Rehabilitation Sciences Graduate Student Society	2016-Present
٠	Heart and Stroke Foundation	2013-2015
	Learning it Together, Western University	2012, 2014-2015

Skills

- Knowledge of SPSS statistical software
- Extensive experience with literature review research and the use of research databases such as CINAHL, Scopus, and PsychINFO
- · Proficient in Microsoft Word, Excel and PowerPoint

Page 3