

**TRIPLE JEOPARDY:
CAREGIVING CHALLENGES, CULTURAL BARRIERS, AND
PRECARIOUS SUPPORT AMONG UNPAID ETHNOCULTURAL CAREGIVERS
IN OTTAWA**

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Keywords

caregivers, seniors, ethnocultural communities, social isolation, social determinants of health, health services, social support, Ottawa

Abstract

This community-based participatory research study used a social determinants of health framework to understand whether and how social isolation is an issue for unpaid caregivers from ethnocultural communities who care for seniors. Despite evidence that Canada's population is both aging and becoming increasingly multicultural, little research has been done to address the unique needs of ethnocultural seniors, and to ensure that they age well with adequate support from both government and community. Further, there has been little research attention given to the experiences of family members and friends from ethnocultural backgrounds who provide unpaid care to these seniors. This study focuses on unpaid caregivers, from six ethnocultural communities in Ottawa, who may experience social isolation while caring for a senior.

Our most significant finding was that unpaid ethnocultural caregivers in Ottawa find themselves in a triple jeopardy: first, caregiving is challenging regardless of age or ethnicity; second, ethnocultural caregivers experience specific challenges due to culture and language barriers, such as difficulty accessing health care services and culturally sensitive long-term care options; and third, many caregivers rely on community programs as a main source of support; however, these programs are precarious due to a lack of adequate or reliable funding.

These findings provide a step towards understanding the factors associated with the social isolation of unpaid caregivers from ethnocultural communities in Ottawa. The stories and experiences explored in this study pointed to several social determinants of caregiver health that can impact their social isolation.

1 Introduction

Problems associated with social isolation and ‘informal’ unpaid caregiving have been identified as important challenges in addressing the needs of Canada’s growing older population (Carstairs & Keon, 2009; National Seniors Council, 2017) and in supporting ‘aging in place’ policy directions that aim to enable aging at home (Government of Ontario, 2012). To date, little research has investigated how these issues may affect the significant population of ethnocultural immigrants to Canada, particularly when these ethnocultural communities face language and cultural barriers upon integration into Canada. These questions are pressing in Canada, where twin demographic trends have made “aging in a foreign land” (Kalache, 2013) an increasingly common experience among seniors (Durst, 2005). The first trend is associated with Canada’s aging population; in 2015, one in every six people (16.1%) was aged 65 years or older and by 2024, this number is expected to reach 20.1% of the total population (Durst, 2005; Statistics Canada, 2015a). The second trend refers to the increase in Canada’s diversity (Durst, 2005). It is estimated that in 2011, approximately one in every five individuals (22%) in Canada was born outside of the country, including 4.5 million seniors (National Seniors Council, 2017). By 2036, it is projected that almost one in three Canadians will be an immigrant, and one in two will be an immigrant or second-generation person with at least one parent born abroad (Statistics Canada, 2017). As Canada experiences an increase in its aging population and diversity, it is important to analyze and address the needs of ethnocultural seniors. Amongst this needs assessment, a focus on the support systems that are available to ethnocultural seniors is required, including the contributions made by unpaid caregivers in the community.

In the context of elder care, the term ‘informal care’ has been defined as “unpaid care provided by family members, friends, and charities” (He & McHenry, 2016, p.829). While some

may label this type of non-compensatory care as ‘informal’, this term comes with inaccurate assumptions about the nature of the work — including that it is somehow less efficient, less organized, or less professional compared to that of ‘formal’ care (Ceci, 2012). Therefore, for the purpose of this paper, the term ‘unpaid caregiver’ will be used (and shortened to ‘caregiver’) to refer to individuals who provide unpaid care to a family member or friend over 65 years of age.

At some point in their lives, almost half of all Canadians will provide care for “a family member or friend with a long-term health condition, disability or aging need” (Sinha, 2015). Currently in Canada, more than 2 million family members, friends and neighbours carry out approximately 80% of the caregiving work provided to seniors (Canadian Institute of Health Information [CIHI], 2010; Williams et al., 2016). Yet, caregivers in Canada are only gradually being recognized for their important role in enabling their loved ones to continue living at home (Sinha et al., 2016).

In Canada, caregiving responsibilities have been observed as being shifted from paid health professionals to unpaid family members and friends in an attempt to decrease government health care spending (Williams et al., 2016). Research has indicated that this shift results in high levels of caregiver stress (Giesbrecht, Crooks, Williams, & Hankivsky, 2012) and feelings of frustration, powerlessness, loneliness, anxiety, fear and being overwhelmed (Campbell et al, 1998; Rudd et al., 1999). When caregivers come from ethnocultural backgrounds that are under-represented in Canada, the sources and experiences of stress could be unique (Guberman & Maheu, 2004). When immigrants first arrive to Canada they are typically healthier than the general population; however, after their arrival, their health status begins to decline below that of the general population. This phenomenon is known as the Healthy Migrant Effect (Ng, 2015), which could be a result of various changes related to an individual’s physical and social

environment. Immigrant health research has documented the struggles caused by transnational migration (De Jong Gierveld, Van der Pas, & Keating, 2015; Hong, 2010; Metcalfe-Hough, 2015; Schumacher & Meleis, 1994), including the experience of being unable to speak the prevalent language and facing barriers due to racism and ageism (Cho, 1987; Meleis, Sawyer, Im, Messias & Schumacher, 2000; Messias, 1997). Some immigrants may also experience mistrust of medical professionals due to their inability to communicate their health concerns and cultural norms in their own language (Dahal, Qayyum, Ferreyra, Kassim, & Pottie, 2014). Furthermore, seniors who do not speak either of Canada's official languages are at greater risk of being socially isolated (De Jong Gierveld et al., 2015).

Social isolation has been recognized as a global public health issue (Goll, Charlesworth, Scior, & Stott, 2015). In health research, the terms loneliness, social exclusion, alienation, and social isolation are often used interchangeably to refer to the experience of living with few, if any, meaningful relationships or social contacts (Goll et al., 2015; Keefe, Andrew, Fancey, & Hallet, 2006; Williams et al., 2016). Although social isolation is often linked with loneliness, the critical distinction is that social isolation is an objective condition, while loneliness is a subjective experience (Menec, Newall, Harasemiw, Mackenzie, & Shooshtari, 2016). A person can experience loneliness without experiencing social isolation and, conversely, a person can be socially isolated without feeling lonely (National Seniors Council, 2014). For the purpose of this study, social isolation and loneliness were quantitatively measured via caregivers' responses to the 2012 Canadian General Social Survey. Due to the nature of qualitative research, participants in our focus groups and interviews were considered 'socially isolated' if they shared with a member of the research team that they lacked social interaction with their community.

Caregivers can feel isolated when they have little or no independence from their care

recipient (National Seniors Council, 2017), or when they feel unsupported in their caregiving responsibilities (Sanders, 2007). Further, out of a reluctance to burden others with their stress, caregivers may isolate themselves when their current informal support networks do not demonstrate an interest in their caregiving responsibilities or challenges (Sanders, 2007).

Cultivating multiple group memberships could protect against isolation and improve health by allowing individuals to experience meaningful social relationships and support (Jetten et al., 2015; Steffens, Cruwys, & Haslam, 2016). Isolation can result in many negative health impacts, including poor mental health, stress, decreased social skills, problematic coping strategies, and risk of premature death (Choi, Irwin, & Cho, 2015; Cornwell & Waite, 2009; Courtin & Knapp, 2015; Federal/ Provincial/Territorial [FPT] Ministers Responsible for Seniors, 2007).

This project considers whether and how social isolation affects unpaid caregivers from various ethnocultural communities in Ottawa who provide care to seniors. We begin by introducing the conceptual framework for this study: the Social Determinants of Health. Next, background information is provided on the policy context at the national, provincial, and local levels. Then, the rationale for this study is articulated, along with some brief background on our community partner, the Social Planning Council of Ottawa (SPC). We lay out the purpose of the study, outline our research questions along with the methods undertaken to conduct this research and include information about data collection and analysis. Lastly, we share the results of our study, along with a discussion of the main findings and their implications, limitations, and our knowledge dissemination plan.

2 Conceptual Framework

To understand whether and how social isolation is an issue for unpaid caregivers from ethnocultural communities in Ottawa, this study uses a Social Determinants of Health (SDoH)

framework. The SDoH framework provides an alternative lens to looking at health status, in which biological factors are not of utmost importance (Braveman & Gottlieb, 2014). The SDoH framework asserts that health is not the product of personal lifestyle choices, but rather, by a combination of social factors and living conditions (Canadian Council on Social Determinants of Health, 2015; Romanow, 2004). These factors and living conditions are the social determinants of health. In Canada, 14 social determinants of health have been identified, which include: income and income distribution, unemployment and job security, employment and working conditions, housing, education, health services, gender, early childhood development, food insecurity, disability, race, Aboriginal status, social safety network, and social exclusion (Mikkonen & Raphael, 2010). These social determinants of health are interconnected and have both direct and indirect effects on health outcomes (Braveman, 2011).

In 2011, the SDoH framework was adopted by the World Health Organization (WHO) to oversee its global health efforts (World Health Organization [WHO], 2012). Following the WHO, other countries around the world have developed their own unique SDoH frameworks. For example, the U.S. Office of Disease Prevention and Health Promotion outlined their framework in the *Healthy People 2020* initiative ([ODPHP], 2017). The WHO and American frameworks are slightly different from Canada's, as they include the following determinants of health: language, culture, stress, and transportation (ODPHP, 2017; WHO, 2003; WHO, 2008). Although these determinants might be applicable to our population of interest, we will draw from the Canadian list, with consideration of how it includes and reflects our study population.

It is important for Canadian policy makers to recognize that the SDoH can influence the ways in which caregivers participate in their community, and can have an impact on their overall quality of life. A recent study examining caregivers of seniors revealed that caregiving is

complex (Chappell, 2016), and that multiple SDoH may have a direct impact on the caregiver's health and their ability to manage their responsibilities (Schulz & Sherwood, 2008).

In the literature, the most significant SDoH affecting caregivers' health and well-being include: income, unemployment, housing, and education. Caregivers can experience financial pressures as a result of their caregiving responsibilities due to out-of-pocket expenses for their care recipients (Turcotte, 2013). Caregiving can also interfere with the caregiver's ability to perform paid work (Cranswick, 1997), which can result in financial insecurity (Campbell et al., 1998), and unemployed caregivers typically experience higher levels of caregiver burden compared to those who are employed (Chappell & Reid, 2002; Dhandapani et al., 2015). Economic factors, such as low income and lack of affordable housing, are risk factors for social isolation (National Seniors Council, 2014). Furthermore, a lack of education (Ronson & Rootman, 2009), poverty and economic hardship, and other factors such as cultural and language barriers, particularly among immigrant populations, can lead to poorer health conditions (Simich, 2009; Simich, Hamilton, & Baya, 2006). In addition, precarious or temporary working conditions can affect access to health information and services for immigrant populations (Oxman-Martinez, Hanley, Lach, Khanlou, Weerasinghe, & Agnew, 2005; Simich, 2009). This demonstrates the importance of utilizing a SDoH framework that sees the interrelation between multiple social factors and health and well-being.

Communicating effectively with health professionals requires adequate access to health services, which is another important SDoH. Health services is defined as not only "the availability of required services, but also how the services are delivered at point of care" (McGibbon, Etowa, & McPherson, 2008, p.24). Access to health services includes timely access to care. For example, wait times to see medical professionals can create anxiety for both patients

and their caregivers, which can affect their ability to cope with day-to-day activities (Liddy et al., 2016). More specifically, wait times associated with obtaining a publicly-funded long-term care bed can create a concern for seniors and their caregivers, as seniors may require acute or alternate level of care during this waiting period (Sivananthan, Doupe, & McGregor, 2015).

While wait times can increase stress levels among caregivers, there are also factors, such as gender, disability, and race, that may indirectly lead to stress and negative health outcomes. Around the world, women are predominantly providing unpaid care for family members and are often faced with many demands (Sharma, Chakrabarti, & Grover, 2016). As a result, caregivers can face significant health consequences, including depression (Lero, Keating, Fast, Joseph, & Cook, 2007), and physical and mental illnesses or disabilities associated with caregiving responsibilities for older adults (Fast, 2015). When caregivers are from ethnocultural backgrounds that are under-represented in Canada, health issues can present themselves in unique ways within and among groups depending on social location, specifically with reference to race, ethnicity, and class (Guberman & Maheu, 2004). For example, according to research conducted with Aboriginal communities, social support has been shown to be an important social determinant of health associated with caregivers' decreased experiences of social isolation (Crosato, K. E., Ward-Griffin, C., & Leipert, B., 2007).

An important and related construct to social support and isolation is social identification. Social identity is often the basis for social support, and refers to an individual's self-concept of their perceived membership in a social group, including the values and significance that they associate with being a member of that group (Hogg & Vaughan, 2002; Tajfel & Turner, 1979). Social identity is often a determinant of health-related behaviours, coping mechanisms, self-esteem, as well as other mental and physical health outcomes (Haslam, Jetten, Postmes, &

Haslam, 2009). Social identity theory seeks to understand the meanings associated with belonging to a social group, including the strong connections that are built with others (Cameron, 2004; Doosje, Ellemers, & Spears, 1995; Tajfel & Turner, 1979). In this vein, cultural practices, language, and race can serve to shape a common social identity among ethnocultural group members (Rummens, 2001), and often provide the foundation for meaningful social networks.

Social networks include the quantifiable interactions that individuals have, including the number and frequency of contacts, and the density of their network (Davidson, 2014). Everyone needs social support to survive and thrive; however, caregivers experience particular barriers to accessing and maintaining social support due to their care responsibilities (Ministry of Health and Long-Term Care, 2009). Difficulty accessing or maintaining social support can lead to social exclusion among both caregivers and care recipients (Ae-Ngibise et al., 2015; Dhalberg & McKee, 2016), which refers to the unequal opportunity of some groups of individuals to participate and engage in society (Mikkonen & Raphael, 2010). In this regard, while the Canadian SDoH framework provides a useful lens through which to examine caregiving challenges and health, it is also important to consider the context in which care work occurs among ethnocultural communities in Ottawa from a policy perspective.

3 Policy Context

3.1 National and Provincial Context

In what follows, the policy context to the daily life of the unpaid caregivers who participated in this research is outlined. Policies influence and shape how care is provided, and how caregivers experience caring and thus is important in shaping caregiver relationships with the social determinants of health. In Canada, health care is governed by the *Canada Health Act* (Government of Canada, 1985). However, long-term care (LTC), including home care, is not

included in the *Act*, is therefore not federally-regulated, and thus falls to the provinces to manage (Sivananthan, Doupe, & McGregor, 2015). Canadian provinces have implemented their own variations of LTC policies (Armstrong & Armstrong, 2008; Gray, 2013; Health Council of Canada, 2012, Sivananthan, Doupe, & McGregor, 2015). For unpaid ethnocultural caregivers, government policies related to long-term care, home care and financial assistance play key roles in shaping their everyday living conditions (Canadian Council on Social Determinants of Health, 2015; Romanow, 2004).

The federal government provides some very limited financial benefits to support Canadian unpaid caregivers. However, these benefits do not fully compensate caregivers for the intense financial pressures they may experience as a result of their caregiving duties (Lilly, Robinson, Holtzman, 2012). In the 2012 General Social Survey, it was reported that only 20% of Canadian caregivers received financial support to offset the costs of caregiving (Sinha, 2015). The first of these federal benefits are two tax credits that can be claimed by individuals who care for seniors: the ‘caregiver amount’ and ‘family caregiver amount.’ The ‘caregiver amount’ enables caregivers to claim up to \$4,667 if they have a dependent who: (1) is over 18 years old, (2) has a net income of less than \$20,607 and, (3) is a relative (either the caregiver’s or the caregiver’s spouse’s parent or grandparent born in or before 1951), or someone with a physical or mental impairment (Canada Revenue Agency, 2017). According to the 2017 Federal Budget, these two benefits will soon be replaced by the “Canada Caregiver Credit,” with broader eligibility criteria which allow caregivers who do not reside with their care recipient to benefit equally from this credit (Government of Canada, 2017).

In 2004, the federal government introduced the second federal benefit: the *Compassionate Care Benefit* (CCB), an Employment Insurance (EI) for caregivers of individuals

at the end-of-life (Giesbrecht et al., 2012). The CCB aims to provide income assistance and job security to individuals who temporarily remove themselves from the workforce to provide palliative care (Giesbrecht et al., 2012; Government of Canada, 2016). This EI support is limited to a subset of caregivers, as the eligibility criteria is restrictive (Giesbrecht et al., 2012; Government of Canada, 2016). These criteria can be an obstacle for caregivers, and especially so for ethnocultural caregivers. Since immigrants in Canada can face greater barriers to accessing part-time and full-time employment and management positions due to institutionalized racism in the labour market (Kunz, Milan, & Schetagne, 2000; Galabuzi, 2006; Pendakur, Mata, Lee & Dole, 2000), discriminatory policies may push racialized caregivers into lower income brackets, where they are unlikely to benefit equitably from EI policies like the CCB, compared to non-racialized caregivers (Pendakur & Pendakur, 1998). Even for eligible caregivers, this amount of financial assistance may be insignificant compared to the costs they may absorb at their loved one's end of life (Giesbrecht et al., 2012).

Since the 1990s, rising health care costs in Ontario have put increasing pressure on the government to curb provincial health care spending. The solution was the unfolding of the neoliberal policy priority of 'aging in place,' which has shifted health care out of publicly-funded hospitals into the community setting, and inevitably, into people's homes, where the responsibility for care falls to the family (International Federation on Ageing [IFA], 2012; Ontario Seniors' Secretariat, 2013). As a result, the number of home care patients served by the CCACs has increased 101% in the last decade (OACCAC, 2014). However, the total funding allocated to the home care sector over that same period did not rise in parallel, but rather increased by less than a quarter of a percent (OACCAC, 2014).

In Ontario, home care is provided through 14 Community Care Access Centres (CCACs) (Tourangeau et al., 2014). The CCACs were created by the Conservative government in 1996, in an attempt to create a single, provincial provider of home and community care (Day, 2014). The CCACs are regulated by two acts, *The Long-Term Care Act, 1994* and *The Health Insurance Act, 1990* (Ministry of Health and Long-Term Care [MOHLTC], 2006). *The Long-Term Care Act* has three mandates that are especially pertinent to this study. *The Act* authorizes (1) that a variety of health services be made available to individuals in the home and community setting, (2) that support is provided to individuals caring for loved ones in the home, and (3) that recognition be given to the importance of providing health services in alignment with the patient's personal preferences in terms of culture, language and religion (MOHLTC, 1994). With regard to home care, *The Health Insurance Act, 1990*, ensures that Ontarians receive care that enables them to return home after a hospital procedure or receive the necessary home care services to enable them to age at home (MOHLTC, 2006).

Although the CCACs are regulated by these two *Acts*, the Ontario home care system is said to be in need of improvements (Ontario Health Coalition, 2015). The Ministry of Health and Long-Term Care (MOHLTC) recently announced that this reform is imminent (Porter, 2017). Ontario's Local Health Integration Networks (LHINs) will resume responsibility for providing home and community care, and the CCACs will be dismantled across the province between May and June 2017 (Porter, 2017). The Champlain CCAC, which is responsible for home care in Ottawa, will merge with the Champlain LHIN on May 24th, 2017 (Porter, 2017). Proponents of this reform hope the proposed health care savings from administrative streamlining will go toward patient care, though critics remain unconvinced the new system will lead to better home care services (Porter, 2017).

In 2015, it was reported that Ontarians felt that their access to home care was limited and unorganized (Ontario Health Coalition, 2015). In 2010, there were a reported 10,000 Ontarians waiting to access home care services and this number had remained constant since 1998 (Ontario Health Coalition, 2011). These system shortcomings have resulted in part due to the previous funding model (Ontario Health Coalition, 2015). When the CCACs were first developed to provide home and long-term care placement in Ontario communities (Day, 2014; OACCAC, 2014), they were established under a “competitive bidding” model (Ontario Health Coalition, 2011), in which both for-profit and not-for-profit home care providers competed to win service referrals (Day, 2014). By employing this model, the CCACs ensured that service providers always delivered care at the lowest possible cost (Day, 2014). This tendering process has been linked to decreased quality of care (Chappell, 2011) and fragmented and disruptive service delivery (Ontario Health Coalition, 2015). As such, in 2012, a long-term performance-based tendering process was enacted, with competitive bidding only being allowed under special circumstances (OACCAC, 2014). Although the competitive bidding model has been dismantled, the home care system is still managing the fragmentation that it left behind (Ontario Health Coalition, 2015). For example, public funds continue to travel through four administrative levels before the health professionals receive their payment (Ontario Health Coalition, 2015), and an extensive administrative system is in place to manage 1,500 different service arrangement terms and conditions (OACCAC, 2014). The “competitive bidding” model, while no longer the current system per se, has resulted in a fragmented system where cost-cutting mechanisms are fostered (Day, 2014) and inadequate access to care persists (Ontario Health Coalition, 2015).

In an attempt to manage costs, a phenomenon known as ‘task-shifting’ became prevalent in Ontario’s home care system (Barken et al., 2015). In the literature, task-shifting refers to the

delegation of health care tasks from regulated health professionals to unregulated, lower-paid health care workers (Barken et al., 2015; Zeytinoglu, Denton, & Brookman, 2014). In the context of this study, however, the term task-shifting is applied to the shift of health-related tasks from paid health professionals to unpaid caregivers.

The home care literature highlights the tension that exists between the government's need to cut health care costs and its promotion of 'aging in place' (Wiles, Leibing, Guberman, Reeve, & Allen, 2011). Scholars who have critically examined this tension argue that it results in chronically ill seniors losing their ability to exercise autonomy over place of care (Clemmer, Ward-Griffin, & Forbes, 2008; Giesbrecht et al., 2012; Wiles et al., 2011). *Living Longer, Living Well*, written by Dr. Sinha on behalf of the Government of Ontario (2012), acknowledged that successful aging requires government funding to be allocated to areas beyond health care, including social supports and senior programming. In order to facilitate successful 'aging in place', key social determinants of health, such as housing and social safety networks, as well as the wishes of seniors and their families, must be considered (IFA, 2012; Wiles et al., 2011). The *Healthy Homes Renovation Tax Credit*, which financially supported caregivers and seniors when mobility modifications needed to be made to their home (The Ontario Seniors' Secretariat, 2013), was an example of the government considering broader social determinants of health; however, this tax credit was discontinued in the taxation year of 2017 (Government of Ontario, 2016).

The government can no longer rely on the traditional family structure to shoulder the vast majority of home care due to changing family structures (Guberman, Lavoie, Blein, & Olazabal, 2012; Guberman & Maheu, 2004; Guberman et al., 2006). In order to sustain good health and quality of life, seniors require a comfortable environment that is age-friendly, allows

them to socially engage with others, and provides them with access to various health and social services (Plouffe et al., 2013). Fortunately, Ottawa launched its Age-Friendly City framework in 2006 and has worked to make the city more friendly for seniors ever since (The Council on Aging, 2017a).

3.2 Aging in Ottawa

The City of Ottawa and the Council on Aging of Ottawa have targeted initiatives that aim to create an inclusive city of Ottawa for all seniors. In 2007, the WHO developed *Global Age-Friendly Cities: A Guide* (WHO, 2007) to encourage cities around the world to consider how to promote the inclusion of older adults. Ottawa has made a commitment, under the direction of The Council on Aging of Ottawa, to join the age-friendly movement. The Council on Aging of Ottawa aims to make progress in each of the eight categories outlined by the WHO through the *Age-Friendly Community Action Plan* (The Council on Aging, 2017a). These eight categories are: outdoor spaces and city buildings, transportation, housing, communication and information, social, recreational and cultural participation, civic participation and volunteering, community support and health services, respect and social inclusion (The Council on Aging, 2015). The Council's latest 2015-2016 Plan outlines key objectives that hope to make a positive impact on seniors in Ottawa; however, more focus could be put on ethnocultural seniors, as well as ethnocultural caregivers. Nonetheless, listed under both the social, recreational, and cultural participation category and the community support and health services category, the Council aims to partner with Jewish Family Services (JFS) of Ottawa to increase the utilization of their Diverse Seniors Services program (The Council on Aging of Ottawa, 2015). This program offers social, physical and cultural activities and case management, transportation, and friendly visiting to ethnocultural seniors in more than nine different languages (The Council on Aging of Ottawa,

2015; JFS Ottawa, 2017). Finally, there is a goal to implement a friendly visiting program for isolated seniors and a Seniors' Outreach Program for Chinese-speaking seniors to help them attend medical appointments (The Council on Aging of Ottawa, 2015). This Plan, however, is now somewhat out of date and a program evaluation has not yet been conducted.

Ottawa's *Older Adult Plan 2015-2018* was approved by City Council on October 28, 2015 (Community and Protective Services, 2015), and outlines the main objectives to be undertaken to make the city more age-friendly (City of Ottawa, 2015). The Plan is built on evidence-based research, consultations with stakeholders, and input from municipal departments (City of Ottawa, 2017). The Action Plan has eight strategic areas and 51 associated measures to be implemented by the end of 2018. One of the goals is to "reach out to older adults from diverse backgrounds to inform them about City programs and services for older adults" and to target "isolated and low income seniors" (City of Ottawa, 2015). Despite its impressive array of goals to be accomplished in the next two years, the Plan lacks focus on the needs of immigrant groups in Ottawa.

Ottawa has a rich multicultural population, ranking sixth highest in Canada for proportion of foreign-born individuals (Employment and Social Development Canada [ESDC], 2016a); nearly one in every five dwellers in Ottawa are from a visible minority population (ESDC, 2016a) (see Appendix A). Therefore, when the Social Planning Council (SPC) and six other Ottawa-based organizations, including the Council on Aging of Ottawa, Catholic Immigration Centre-Ottawa, and four community resource centres, were approved in 2015 for funding from Employment and Social Development Canada under the auspices of the "New Horizons for Seniors" initiative, a gap started to be addressed (ESDC, 2016b). The SPC was approved for "Creating Community for Isolated Ethnocultural Seniors" (CCIES), a collaborative project that provides support to 18 different grassroots ethnocultural groups in Ottawa. This project is

managed by a paid, part-time coordinator who coordinates all aspects of the program. Some of the coordinator's activities include project management, capacity-building and partnerships development, as well as providing resources for the ethnocultural groups supported by CCIES. The goal of CCIES is to reduce isolation for ethnocultural seniors by increasing opportunities to connect within the ethnocultural and wider communities. CCIES provides culturally appropriate recreation, workshops and community events, which facilitate the building of social networks, and improvement of peer support and well-being. Each of the ethnocultural groups participating in CCIES has one or two leaders, or volunteer coordinators, who are members of their respective ethnocultural communities. A monthly meeting organized by the SPC coordinator provides a space for these coordinators to share strategies on their respective programs and exchange support, to collaborate on strategies to reduce isolation in isolated seniors in ethnocultural communities, and to receive updates on current health and wellness programs for dissemination to their communities. These meetings are also an opportunity to meet with community partners, like Ottawa Police, the Alzheimer's Society of Ottawa, and Renfrew County, and to learn, share and consult on important matters, such as abuse prevention, financial literacy, and healthy living activities. Each coordinator works within their respective ethnocultural group to connect them with mainstream services that support social opportunities and healthy aging. They also reach out to isolated seniors to build social networks, by offering a wide range of social, recreational and cultural activities, and providing opportunities for one-one-one support through personal visits by phone or in-person. Finally, coordinators encourage seniors to become active volunteers in the community (KOSCLC, 2015).

Currently, CCIES reaches 3,026 ethnocultural seniors, of which an unknown proportion are caregivers (The Council on Aging of Ottawa, 2017b). Although the literature states that

ethnocultural caregivers in general tend to be younger, are more likely to have lower socioeconomic status, are less likely to have a spouse, and are less likely to seek out social support from their friends and family to help them with their caregiving duties (Pinquart & Sörensen, 2005), there is a knowledge gap regarding unpaid ethnocultural caregivers in Ottawa.

4 Study Rationale

The widespread acceptance that Canada is aging quickly and becoming more diverse has not lead to a concomitant rise in research dedicated to the needs of senior immigrants, nor their unpaid caregivers who provide high levels of support. Our review of the literature shows that the needs of unpaid caregivers are abundant, and social isolation is one significant factor that shapes their psychological well-being. When immigrant seniors experience language and cultural barriers to social support and access to services, these experiences of isolation may intensify.

There are many reasons why the issues confronting unpaid ethnocultural caregivers of seniors in Canada require researcher and policy maker attention. First, as we have noted, the senior population and ethnocultural communities are growing in Canada. Immigrants do not differ significantly from Canadian-born seniors in terms of their risks for chronic conditions (Vang, Sigouin, Flenon, Gagnon, 2015). The Healthy Migrant Effect explains how immigrants' health deteriorates soon after their arrival to Canada, despite having a higher health status before arriving to Canada (Ng, 2015). Greater longevity means people are often living more years with chronic health problems, requiring more hours of care and support in and out of the home (Boersma, van Weert, Lakerveld, & Dröes, 2014).

Second, since the health reforms of the 1990s, political and ideological shifts have precipitated constraints to state spending on long-term care services across Canada, pushing care out of institutions and into the community (Clemmer et al., 2008), with insufficient spending to

support community services such as home care. These conditions have meant that frail, aging individuals with long-term health care needs are often deprioritized in government-funded home care services in favour of those with acute, medicalized needs, thereby rationing chronically-ill seniors out of state-supported care and offloading it onto families (Giesbrecht et al., 2012).

Funding restrictions affect seniors' access to help with their essential activities of daily living, which are vital to maintaining their autonomy in their homes (Aronson, 2002). When the brunt of paid care work is dropped by home care services, it falls to families to pick up the pieces.

Third, many social policies, such as the *Compassionate Care Benefit* and the caregiver tax credits, reflect the normative expectation that families will provide care for one another, despite the unique circumstances of each family (Treloar & Funk, 2011). The concept of familialism describes the ideological assumption that care for elders (as well as children) is “intimate labour” (Zelizer, 2005), that should be provided by the family in the home setting. Familialism emphasizes that such care is a moral imperative, and any desire to seek help from the ‘outside’ is considered weak or even immoral (Esping-Anderson, 1999; Lewis, 2001). This familial norm is common in many ethnocultural communities (Funk & Kobayashi, 2011), which assume that care not only should, but also must be provided by family. The result is that help-seeking behaviour can be stigmatized, putting extreme pressure on families to make do without support (Funk & Kobayashi, 2011). Pressures to care for seniors at home can diminish caregivers' perceived sense of choice, which in turn can lead to: disempowerment and emotional distress; difficulty accessing much-needed help for either the caregiver or the ill or frail loved one; being shunned from the community if a caregiver tries to seek assistance with their duties; and, internalized feelings of shame or guilt on the part of the caregivers and their loved ones (Liu, Hinton, Tran, Hinton & Baker, 2008).

Fourth, even for many families who desire to care for their elders at home, changing family structures may make it difficult to do so. Structures are shifting due in part to rises in the divorce rate, female employment rate (Treloar & Funk, 2011), and costs of living (Armstrong & Kits, 2001). Higher cost of living, additional caregiving expenses, cuts to services, lower wage earnings of women, and financial difficulties post separation and/or divorce can put female caregivers into financial difficulty (Treloar & Funk, 2011). When the barriers to employment for racialized persons are taken into consideration, the challenges of care become more glaring. Women, in particular, face conflicting expectations to be “‘proper’ and ‘responsible’” in fulfilling their care duties toward children and elders, while also earning a livelihood (Smart, 2003, p.3). Changing family structures can be highly problematic for caregivers, especially women and in particular those from ethnocultural communities (Treloar & Funk, 2011).

Fifth, the possibility of higher taxation to offset costs for improved home care, caregiver benefits and social programming for the critically ill and their carers has largely been stalled in Canada by neoliberal policies promoted by elites, big business and free market ideologies (Neysmith, 2012). In 2015, Switzerland, Norway and Sweden ranked first, second and third as the best countries to live in as a senior. These countries are able to provide for their elders through some of the highest taxation in the world (HelpAge International, 2015). The lack of political will in Canada to economically support caregivers and lack of public will to pay higher taxes continue to be of concern to researchers and laypeople alike, who see the drastic effects of the shrinking welfare state (Armstrong & Armstrong, 2004; Neysmith, 2012). For these reasons and more, the needs of unpaid ethnocultural caregivers should be considered. Fortunately, there are community organizations, like the SPC of Ottawa, who are looking out for the best interests of seniors and caregivers and are doing their part in the effort to support them.

Social Planning Council of Ottawa

Our community partner for this project, the Social Planning Council of Ottawa (SPC), proposed this research study as a part of the “Keeping Ottawa Seniors Connected” (KOSC) program, which brings together six community partners (Ottawa West Community Support, Catholic Centre for Immigrants-Ottawa, Nepean Osgoode-Rideau Community Health Centre, South-East Ottawa Community Health Centre, the Social Planning Council of Ottawa, and the Western Ottawa Community Resource Centre), with the Council on Aging of Ottawa serving as the principal coordinator for this project. The SPC is contributing to the KOSC program through their collaborative project titled “Creating Community for Isolated Ethnocultural Seniors” (CCIES). This research project aims to provide helpful information for the SPC to use in planning and organizing other initiatives with the CCIES.

5 Research Questions

In consultation with our community partner, issues of social isolation in ethnocultural communities were identified. Our research team had a particular interest in care work. Therefore, we combined these two areas of interest in collaboration with our community partner, evolving into two research questions. First, do unpaid ethnocultural caregivers in Ottawa who provide care to seniors experience social isolation? Second, are there differences in experiences of social isolation among unpaid caregivers from different ethnocultural communities in Ottawa who provide care to seniors? We focused on caregivers from various ethnocultural communities in Ottawa who may experience distinct barriers to resources that affect their social engagement and their care responsibilities.

This study also aimed to clarify the challenges faced by ethnocultural caregivers of seniors, in order to contribute to policies and programs that can better support their unique needs. We

expected to find that unpaid caregivers from various ethnocultural communities in Ottawa experience social isolation, and that these experiences of social isolation differ between ethnocultural communities in Ottawa, due to unique cultural norms and expectations.

6 Methods

This community-based participatory research (CBPR) study used a mixed methods approach, including both qualitative and quantitative methods. CBPR recognizes that community members and community organizations possess rich knowledge and, therefore, they are treated as equal partners – rather than “subjects” – throughout the research process (Clark & Ventres, 2016; Ochocka & Janzen, 2014). As a result, our community partner, the Social Planning Council of Ottawa (SPC), was an active participant in the full research process, including: developing the research question, methodology, data collection, and dissemination.

In order to answer the research questions above, the research team conducted secondary analysis on the 2012 Canadian General Social Survey (GSS) (Cycle 26), which was conducted under the *Statistics Canada Act*. The data for this analysis was obtained through the Carleton University’s Library, which hosts a Research Data Centre (an extension of Statistics Canada). The data obtained was stripped of all direct identifiers by Statistics Canada and did not contain personal details such as names, addresses, and phone numbers. The quantitative methods allowed the researchers to capture a national snapshot of caregivers who may experience isolation or loneliness.

In contrast, the qualitative methods involved conducting focus groups and interviews with caregivers from ethnocultural communities in Ottawa, as well as key informants. The SPC helped the research team recruit participants for both focus group and interview sessions. The research team e-mailed a summary of the research project to the SPC (see Appendix B), who

then distributed the summary to the 18 ethnocultural communities participating in the “Creating Community for Isolated Ethnocultural Seniors” project. The volunteer coordinators of these ethnocultural communities shared the research summary with their respective communities to determine the interest of their members’ participation in this study. For those who were unable to attend a focus group session, but were interested in participating in the study, a semi-structured interview was scheduled. In addition, the SPC also recommended a number of knowledgeable persons for key informant semi-structured interviews (see Appendix C). Ethics clearance was obtained from the Carleton University Research Ethics Board for this part of the study.

Focus groups were chosen as the primary tool for the qualitative study as this method goes beyond analyzing facts and figures (Bowling & Ebrahim, 2005). Focus groups provide an opportunity for research participants to share in-depth experiences related to the research question (Leung & Savithiri, 2009). Focus groups also allow for conversations to occur between participants, which often result in meaningful and sometimes unforeseen findings (Leung & Savithiri, 2009). The success of this tool is based on the moderator’s ability to facilitate conversation (Leung & Savithiri, 2009). In order to acquire these skills, all members of the research team received training in conducting focus groups prior to the data collection phase of the project.

In the data collection phase of the qualitative study, a total of five focus group sessions and eight key informant and caregiver interviews were organized and held. The focus groups were held with the following ethnocultural communities: Chinese (2), Indo-Canadian, Polish, and Nepalese. Caregiver interviews were held with members from the Vietnamese, Sri Lankan, and Indo-Canadian communities. Lastly, the key informant interviews were held with those knowledgeable about or connected to the Vietnamese, Sri Lankan, and Nepalese communities

(see Appendix D).

Each focus group was conducted by two members of the research team. Typically one researcher was the lead facilitator of the session (i.e. asking the key questions and ensuring the flow of the discussion) and the other was the note-taker. Key informant interviews were conducted in-person or over the telephone. All focus groups and interviews were audio-recorded. Interpreters were used to facilitate the discussions for two focus groups with the Chinese community and one with the Nepalese community. A fluent Mandarin and Cantonese-speaking student and a fluent Nepalese-speaking student were recruited by the research team to translate and transcribe the respective transcripts. All interpreters, translators, and community leaders who attended the focus groups signed a confidentiality agreement form (Appendix E).

7 Data Analysis

7.1 Quantitative Data Analysis

Secondary analysis of the Canadian General Social Survey (GSS) was conducted using Statistical Package for the Social Sciences (SPSS, Statistics Standard GradPack for Mac 2016, Version 24) software. Data analyses were conducted only with participants who were caregivers and who indicated helping or caring for individuals with “problems related to aging in the last 12 months” ($N=2,470$). To examine differences in caregivers’ social isolation as a function of ethnicity, the 25 ethnic groups captured by the GSS were regrouped into five similar backgrounds: (1) Canadian/British, (2) Aboriginal, (3) European, (4) South Asian/Chinese and (5) Other. This regrouping was necessary to facilitate a one-way analysis of variance (ANOVA) as there were a small number of participants who self-reported belonging to some of the 25 ethnicities. To examine isolation, we recoded the GSS item for our main dependent variable “During the past 12 months, have your caregiving responsibilities caused you to feel lonely or

isolated?” from 1=Yes 2=No, to 0=No, and 1=Yes, such that greater scores on this variable indicated greater self-reported experiences of loneliness or isolation.

7.2 Qualitative Data Analysis

The research team used NVivo software to analyze the transcripts from the qualitative study. Upon completion of 13 transcriptions, using both an inductive and deductive approach, the research team developed a preliminary list of nodes (i.e. themes) to facilitate a unified coding process; this methodology is validated by Bradley, Curry, & Devers (2007). To ensure inter-rater reliability, each transcript was coded twice by two different team members. The first round of coding was completed by the focus group lead facilitator, while the second round of coding was completed by a member of the research team who did not attend the focus group or interview. After the first round of coding was complete, the research team convened to discuss and re-organize the nodes (i.e. themes). This ensured that the codes were interpreted the same amongst all coders. During this process, new nodes were created for new themes and redundant nodes were either removed from the list or merged into other nodes. The result was a finalized nodes list that would be used by all team members throughout the second round of coding. To ensure all transcripts yielded an inter-rater reliability score of at least 80%, the two transcripts were compared (with “coder 1” against “coder 2”) using the “coding comparison query” function in NVivo. The result generated a percentage of agreeability between coders on all nodes. If a node within a transcript provided an agreement score of less than 80%, that transcript was assigned to a reviewer (independent to coder 1 and coder 2) to resolve the conflict. The research team began analyzing the qualitative data once the agreement score reached 80% or higher for all transcripts.

8 Quantitative Results

In the 2012 General Social Survey (GSS), a total of 2,470 individuals reported they had helped or cared for individuals who had “problems related to aging” in the previous 12 months. Of these 2,470 caregivers, 1,358 were females (55%) and 1,112 were males (45%), and their marital status was as follows: married (55.3%), single/never married (21.2%), living common-law (8.0%), divorced (6.4%), widowed (5.8%), separated (3.1%). There was a wide age spectrum within the caregiver respondents, with the majority being between 45 and 64 years old (see Table 1).

Table 1: Age of caregiver respondents.

Age	Frequency	Percent
Valid		
15 to 24	222	9.0
25 to 34	236	9.6
35 to 44	356	14.4
45 to 54	653	26.4
55 to 64	654	26.5
65 to 74	233	9.4
75 years and over	116	4.7
Total	2470	100.0

The province with the highest number of caregivers per capita was Ontario (24.5%), followed by Alberta (10.8%), British Columbia (10.8%), Quebec (10.6%), Newfoundland and Labrador (8.7%), Saskatchewan (8.5%), Nova Scotia (8.4%), New Brunswick (7.0%), Manitoba (6.8%), and Prince Edward Island (3.8%).

8.1 Ethnocultural and Religious Characteristics of Caregivers

The survey captured 25 different ethnicities (see Table 2). To facilitate our statistical analyses, these 25 ethnicities were reclassified into 5 broader ethnic groups: Canada and British Isles, Aboriginal, South Asian and Chinese, all European, and Other (open-ended). Out of these 5 ethnic groups, most caregivers self-identified as being from Canadian and British Isles (65.2%) or European (16.2%) backgrounds. Based on our study's population of interest, it is important to highlight that only 4.0% of the caregiver respondents reported being South Asian or Chinese. Aboriginals represented only 1.9% of caregivers captured by this survey. The remaining caregivers (17.1%) fell under the "Other" category.

Table 2: Ethnic background of caregiver respondents (25 categories).

	Ethnic Background	Frequency	Percent
Valid	All other multiple origins excluding Canadian, British Isles	108	4.4
	All other multiples with Canadian, British Isles or French	28	1.1
	Canadian and other	41	1.7
	French and other	59	2.4
	Canadian and French	45	1.8
	British Isles, French and other	41	1.7
	British Isles and other	284	11.5
	British Isles and French	68	2.8
	British Isles and Canadian	43	1.7
	British Isles (multiples with English, Scottish, Irish)	245	9.9
	All other single origins	67	2.7
	South Asian only (East Indian, Sri Lankan, Pakistani, Punjab)	48	1.9
	Other European (single response)	154	6.2
	Polish only	25	1
	Dutch only (Netherlands)	39	1.6
	Chinese only	50	2
	Ukrainian only	41	1.7
	Aboriginal only (North American Indian, Métis or Inuit)	48	1.9
	Italian only	57	2.3
	German only	84	3.4
	Irish only	106	4.3
	Scottish only	100	4
	French only	114	4.6
	English only	273	11.1
	Canadian only	163	6.6
Total	2331	94.4	
Missing	Don't know	102	4.1
	Not stated	37	1.5
	Total	139	5.6
Total		2470	100

The GSS also provides data on religious characteristics. Approximately one-third of the caregivers surveyed (33.9%) identified themselves as Roman Catholic. However, the second most frequently reported group (18.7%) of caregivers did not associate with any religious denomination. The remaining caregivers reported being affiliated with the following religions: “Other” (16.2%), United Church (8.2%), Anglican (7.3%), Baptist (2.2%), Lutheran (1.8%), Presbyterian (1.7%), Pentecostal (1.4%), Eastern Orthodox (1.3%), Islam (0.9%), Sikh (0.8%), Jewish (0.7%), Buddhist (0.6%), Jehovah's Witnesses (0.6%), Hindu (0.5%), and Ukrainian Catholic (0.3%).

8.2 Caregivers’ Activities and Health Status

Upon inquiring about the main activity that caregivers were involved in during the past 12 months, the most frequent responses that caregivers indicated were that they were working at a paid job or business (61.9%), or that they were retired (19.3%). Importantly, only 0.2% indicated that providing care to a family member or friend for a long-term health condition was their main activity. The remaining caregivers indicated their main activity was: going to school (7.1%), household work (3.2%), caring for children (3.0%), long-term illness (2.8%), looking for paid work (1.7%), volunteering (0.3%), “other” (0.2%), and maternity/paternity leave (0.1%).

It was found that 7.1% of caregivers received help for their own health conditions. Caregivers were prompted to answer the question “What is the main health condition or problem for which you have received help?” only if they had answered “yes” to the following two questions: (1) “During the past 12 months, have you received help or care for a long-term health condition or a physical or mental disability?” and (2) “During the past 12 months, have you received help for problems related to aging?”. Only 7.1% of respondents answered “yes” to the

first question, whereas 92.95% of respondents answered “no”. If caregivers responded with “no” to the first question, they were presented with the second. A total of 4.7% of respondents answered “yes” to the second question, and 95.3% of respondents answered “no”.

The caregivers who had answered “yes” to one of the above questions were then asked about their main health condition or problem for which they received help. This may explain the relatively small percentage of caregivers (7.1%) who answered “yes” to this specific survey question. It is important to note that some caregivers with health conditions may have been excluded from this survey question based on their own self-perceptions. Those who did not consider their health problem to be a “long-term health condition, or physical or mental disability” and answered “no”, did not have the opportunity to answer this question. In addition, those caregivers who did not consider their main health condition or problem to be age-related were excluded from this survey question. Also, caregivers who reported their age as 64 years or under were not asked this question even if their condition could relate to aging. Table 3 provides a list of the main health conditions or problems that caregivers self-reported.

Table 3: Main health condition or problem for which caregivers received help.

Health Condition	Frequency	Percent
Other	25	1
Mental illness (e.g., depression, bipolar disorder, mania or schizophrenia)	22	0.9
Aging / old age / frailty	19	0.8
Cancer	17	0.7
Arthritis (e.g., rheumatoid arthritis, osteoarthritis, lupus or gout)	16	0.6
Injury resulting from an accident	15	0.6
Back problems	13	0.5
Cardiovascular disease (including angina, heart attack, stroke or hypertension)	12	0.5
All other neurological diseases (e.g., Parkinson's disease, multiple sclerosis, spina bifida or cerebral palsy)	10	0.4
Digestive disease (e.g., celiac disease, irritable bowel syndrome, stomach ulcers or Crohn's disease)	6	0.2
Fibromyalgia, chronic fatigue syndrome or multiple chemical sensitivities	5	0.2
Joints problems	3	0.1
Developmental disability or disorder	2	0.1
Alzheimer's disease or dementia	2	0.1
Migraine	2	0.1
Diabetes	2	0.1
Eye problems	1	0
Asthma	1	0
Kidney disease	1	0
Osteoporosis	1	0
Total	175	7.1
Not Asked	2295	92.9
Total	2470	100

8.3 Social Isolation or Loneliness across Ethnic Groups

In our descriptive analysis, it was found that 145 out of 1,433 caregivers reported that during the previous 12 months their caregiving responsibilities caused them to feel lonely or isolated. A one-way ANOVA conducted to analyze whether ethnic group differences existed with regard to respondents' self-reported social isolation or loneliness revealed no significant differences across the ethnic groups, $F(4,1344)=.430, p=.747$.

8.4 Social Isolation or Loneliness and Age of Caregiver

A one-way ANOVA was conducted to observe whether or not there were differences in self-reported social isolation or loneliness as a function of caregiver age. Before the analysis was conducted, the age variable was split into two groups: caregivers 65 years of age and older, and caregivers under the age of 65. There was no statistically significant difference between these two groups: $F(1,6485)=.035, p=.851$.

In sum, our quantitative results demonstrate that caregiving is reported to be more common among women, married individuals, those aged 45-64, and working individuals. In addition, our quantitative analysis reveals that there are no significant differences across ethnic groups, suggesting that many caregivers may feel lonely or isolated regardless of their age or ethnicity.

9 Qualitative Results

Our quantitative analysis suggests that caregivers in Canada can experience social isolation or loneliness regardless of age or ethnicity. Building on our quantitative analysis, our qualitative data revealed that caregivers in Ottawa face a triple jeopardy in their conditions of caregiving that shape their caregiving and related social isolation. This triple jeopardy is shaped by the following three findings. First, caregiving is challenging, regardless of age or ethnicity; second, ethnocultural caregivers face cultural and language barriers that make their work more

difficult; and third, the social programming that these caregivers depend upon for support is precariously funded and organized.

9.1 Caregiving is Challenging

The first jeopardy is that caregiving is difficult, regardless of age or ethnicity. Our study participants expressed feeling tired, stressed, and overwhelmed as a result of their caregiving responsibilities. Our participants told us that one major challenge contributing to their stress was “scheduling” medical appointments for their care recipient. However, the work involved with caregiving was often discussed by participants as going beyond the caregiving responsibilities of cooking, shopping, and driving to medical appointments. Participants spoke about wanting more support for home care activities that their loved ones needed, including bathing, eating, cleaning the house, companionship, and physiotherapy. Caregivers told us how caregiving was often challenging as it took over their lives, in that they were always caregiving, no matter what other activities they might also wish to do. One caregiver shared “[I placed] a baby monitor in my room and [my mother’s] room, so every time she moved I could hear it” (Focus group, Polish community). Not surprisingly, caregivers reported that a main source of stress was difficulty maintaining a work-life balance. One interviewee described her attempt to balance being both an employee and a caregiver:

I phoned to report [to] my boss that I cannot come to work today. [...] And that’s why I am [stressed]. I have no people to help me to stay at the hospital with my dad just in case they need [a] translator. My brain, I have to divide in three: home, work, hospital. Stressful. (Caregiver interview, Vietnamese community)

Due to the difficulty in doing paid work while caregiving, this participant eventually made the decision to take an extended leave of absence from work without pay.

Yet, aside from the challenge in maintaining work-life balance, caregivers can face difficulties balancing between their own needs, that of their care recipient, and the rest of their family. A participant who cared for her husband confessed emotionally in a focus group, “At the time, I forgot myself, I forgot about my daughter” (Focus group, Chinese community). The all-consuming nature of care work makes it hard to take a break every once in awhile.

Nearly every single participant in this study, across all ethnocultural groups, expressed the view that caregivers needed opportunities for respite from their care work: “caregivers are really at a loss. They can’t get away and they need some respite or something.” However, participant’s definitions of respite varied. According to a caregiver from the Indo-Canadian community, “respite doesn’t have to be long... [it] can just be conversations.” A participant offered the example of how simple respite can be: a “one hour coffee group, something like that, [where] you learn from someone, what worked, what didn’t.” Based on the discussions that took place in focus groups and interviews, it appears that a key element of respite is emotional and social support, as well as convenience of access. Respite for caregivers of seniors was compared to respite for new parents:

When I [had] my children, we used to have a little group. When the kids would go in the nursery, the mothers that would come to the nursery would get together, and would have coffee [be]cause they were waiting for their children... But when you grow older, you don’t have that kind of group, so you feel, okay so is this my life now? But it isn’t... you don’t have a group to latch onto, to talk about different things. (Focus group, Indo-Canadian community)

Participants described three reasons why caregivers need respite. First, burnout is high because, as one caregiver put it, “it is a 24 hour job.” Second, caregivers are often older adults themselves;

though it used to be primarily middle-aged children caring for their elderly parents, it is now often “seniors looking after seniors...with no respite.” Third, respite is preventive care that values the caregiver’s health needs and allows for their work to be more sustainable. In reference to taking a break from caregiving, one focus group participant from the Indo-Canadian community said:

[...] look at the health of the caregivers, they will live longer – more productive lives and give better services to the people they are taking care of. Cause otherwise, you start getting exhausted and you don’t do your job properly, [because] you are not taking [care] of yourself. You need to take care of yourself.

To be able to offer respite opportunities for caregivers, participants noted that “you need a place to meet, you need funding to coordinate,” and a coordinator to organize activities and say “okay this day we are having a meeting.” As caregivers explained their need for respite care, they also noted that health care services are inaccessible and do not provide enough support to meet their needs.

Accessing home care is an issue for many caregivers. A caregiver from the Indo-Canadian focus group was asked about whether she received services from a nurse or personal support worker. She replied: “I don’t receive. I called once but they said they can’t [come]. It’s fine. Maybe it would be more difficult getting the services.” In response to this caregiver’s statement about being denied home care, the volunteer coordinator in the focus group was fortunately able to come to the caregiver’s rescue. She said, “People who are in charge of these kinds of things, social services, I’m going to meet them again to set up care.” She added: “...those are the kinds of people who have no help available. They fall through cracks because they don’t [...] have a voice.” Home care seems to make a big difference in the lives of

caregivers because it allows them a brief reprieve from their otherwise constant duties. A caregiver said:

My mum currently she has a [CCAC] worker come to my sister[s] place to help her three times a week, three hours a week for the sponge bath, not for meal, we prepare the meal. She can eat by herself. Actually three times a week [for] one hour. That one hour, we can take a break! (Caregiver interview, Vietnamese community)

While the home care received by some seniors is adequate for their needs, for many people it simply is not enough. A caregiver noticed that home care for their loved one was gradually reduced:

I used to get someone in everyday for three hours. They wanted to cut it down to two, I said I need to get out to do some exercise by the time I go there, I change, I do the exercise for an hour, change again, two hours is not enough. Because then by myself I have to shopping, etc. But now that has been cut down. (Focus group, Indo-Canadian community)

Home care is not the only health service that was inaccessible to caregivers. Wait times for various health services was also deemed a challenge that caregivers face, especially in terms of accessing the right care, at the right time. According to a caregiver from the Indo-Canadian focus group, “Usually there is a long waiting time [...] by the time somebody can help, the crisis is over [...].” In the focus group with the Chinese community, caregivers reiterated the frustration of having to demand services over and over, and having to wait a long period before accessing services for themselves or their loved ones: “After I repeated many times, again and again, finally they would sign me up into a specialized clinic but it took time. The waiting time for that is usually 3 to 4 months.” On the other hand, when it came to emergency health services,

the view was mixed. In the focus group with the Polish community, a caregiver stated: “I don’t know what people are complaining about. We have excellent care.” Yet, another caregiver’s perception was that seniors are not the priority in a hospital setting, because she was acknowledged by staff much more quickly in comparison to her 106 year-old mother: “They don’t treat old people the same way as they would treat younger people.”

Overall, participants across ethnocultural communities expressed their strong commitment to being caregivers and their desire to carry out their care activities with excellence. In the pursuit of ensuring their loved ones receive the best care possible, a participant shared their desire to know “...what kind of training I can get to become a better caregiver” (Focus group, Chinese community). Most caregivers across ethnocultural groups voiced the need for training on how to do their work well, specifically how to conduct basic caregiving tasks, such as “feed[ing] the senior citizens”. A focus group with the Chinese community noted the positive long-term effects of training for caregivers, and one caregiver suggested: “It’s just more important from an educational point of view, if in the long-run we can educate people, get them prepared, give them some knowledge, so that when the situation happens, they know how to deal with it.” Another participant stated that, “[t]he quality of taking care will depend on how much the caregiver knows about the disease”. One caregiver noted the struggle of learning about the illness of their loved one:

...at that time, I knew nothing about cancer. And I had resistance to know more about the disease [...] and I had no idea what to do. So I believe apart from thinking about how to take care about the patient, as a caregiver, I think I didn’t use knowledge to improve myself. (Focus group, Chinese community)

Some caregivers expressed that they feel underprepared to carry out complex tasks and handle difficult situations, and shared their anticipation, fear and dread over not knowing what to do “when something bad happens”. Participants from multiple ethnocultural communities reported that there is currently a gap in information regarding what services are available for caregivers in emergency situations. They asked the researchers questions about what programs, services and TV channels are available to help them learn how to do their care work well. Some volunteer coordinators recognized this issue and are currently trying to remedy the lack of information for seniors in their ethnocultural communities. One key informant is working on producing information materials for the Indo-Canadian community:

Yesterday I met with a few people and I said we need an information pamphlet of what situations and what place to call, so I’m going to develop that. But in a crisis situation, people sometimes don’t even know where the help can be available.

Overall, participants would feel more comfortable carrying out complex caregiving tasks if they had accessible training and services.

9.2 Ethnocultural Caregivers Face Additional Challenges Due to Cultural Barriers

In addition to the fact that caregiving is hard, regardless of age or ethnicity, ethnocultural caregivers face a second jeopardy as a result of cultural barriers in accessing and benefitting from health care services in Ottawa. Ethnocultural caregivers participating in our study provided substantial interpretation assistance for their care recipients, especially in their interactions with health professionals in primary care, home care, and long-term care.

Many caregivers in our study spoke about the unavailability of interpretation services in Ottawa’s primary care facilities, which requires them to “depend on family” and friends for interpretation if they do not speak English themselves. One caregiver shared that she had to make

an international call during her doctor's appointment to get the help she needed: "Some words at the hospital, I didn't understand, so I had to call to my nephew in the United States to translate them for me" (Caregiver interview, Vietnamese community).

Caregivers explained how they go to great lengths to prepare for appointments. For example, one caregiver shared that since he could not have family present with him, he had to seek out interpretation assistance strategically in advance of each appointment:

Before, if I needed to see a doctor, I had to prepare the terminology for my kids in advance, like a student preparing lessons before class. For example, how to say pacemaker, how to say heart, fibrillation, etc. My kids needed to go over [this] beforehand. Now they don't need to do so. They don't need to ask for leave from work and prepare so much. (Focus group, Chinese community)

Even for seniors who speak some English, the level of proficiency required to interact with, and ask questions of, their health professionals is sometimes beyond their English fluency level. One caregiver from the Sri Lankan community, whose parents speak some English, noted this challenge:

But even going to the doctor sometimes... it would help if they had a translator with them, because sometimes... even if they explain the medical terms and what not, they don't know what questions to ask as well. It doesn't come to them right away, and by the time they go home and they want to ask the questions, you know, they have to make another appointment and wait for a few months.

Language barriers can also be an issue in home care. According to our participants, home care staff rarely speak the same mother tongue as the caregivers in our focus groups. One caregiver shared, "I would rather them not come if they don't do that for me. I asked if there was

anyone who could speak Cantonese. They said no one.” Home care staff do not always speak English either. According to another participant from the focus group with the Chinese community, “The workers who help us are also not very fluent in English. They might not do the things that we instruct them to do. They have their own way of practice.” This unavailability of home care in one’s own language presents challenges for caregivers. In addition to basic communication issues, the majority of participants expressed their disappointment with the lack of culturally sensitive long-term care in Ottawa. When caregivers were asked how they might use a magic wand to help support caregivers in their community, participants spoke of the desire for culturally sensitive long-term care homes that meet their community’s cultural and linguistic needs. One participant noted:

The ideal is aging at home and having someone support you there, but also you need some kind of seniors home [...] that will cater to the community whose needs are quite a bit different culture-wise, language-wise. So that’s another issue that will need to be addressed at some point. (Focus group, Indo-Canadian community)

Participants felt that facilities should cater to patients in a few ways: they should offer culturally appropriate food options and recreational activities at reasonable costs and minimal wait times, and staff should speak the language of their patients. As one caregiver put it, “We don’t need a fancy place, at least [a] standard for senior citizens, especially for Vietnamese people. They can get services in their languages, then [staff] can understand [them].” For some caregivers, the possibility of being in a home with people who speak their mother tongue is so compelling that they are willing to relocate to other cities, such as Toronto. One participant from the Polish community shared her reasons for applying to a Polish long-term care home in Toronto, despite the five year wait list: “The reason is not only food, but it is entertainment as

well.” It is a meeting place for the Polish Canadian Women’s Federation, enabling long-term care patients to remain engaged in their social activities. The participant noted:

The ladies that live there attend those meetings, so they have meetings with the younger generation... the youngest is 30-something and the oldest one is 94, 95. So they are still a part of [the] organization, part of life. They have not completely abandoned [it] ... and that’s what I think is good that the younger members are sort of taking care of the older, visiting them, meeting and talking to them. (Focus group, Polish community)

Despite her proficiency in English, this caregiver was also concerned about the possibility of needing help from Polish-speaking staff in her later years. “I don’t know if I’m going to lose my English or not, but it’s a possibility, because it happened to my mother.” For many reasons, seniors are keen to find culturally appropriate housing options in later life, and are willing to go to great lengths to find it.

A key informant from the Indo-Canadian community felt so strongly about the need for culturally appropriate long-term care for her community that she was willing to open a home herself. The key informant stated:

[My] long term plan is to open a seniors’ home for South Asians...same ethnic background, culture...if they are all together in one place I am sure that their isolation, sadness, depression will be [...] reduced [compared to] what they are experiencing now.

Caregivers from several ethnocultural communities described a need for specialized long-term care facilities for their particular populations. A key informant stated that Ontario long-term care homes currently do not have the resources to support people “who ha[ve] different food and religious preferences”. Further, group activities during the day are one of the main benefits for Canadian seniors to enter into long-term care homes. However, a key informant from the Indo-

Canadian community pointed out that not all activities are enjoyed equally across cultures:

I noticed that [Canadian] seniors have lot of [...] activities to do, like bingo, and they are so happy and they play cards, [...] and compared to that, the South [Asian] cultures [...] don't play bingo, [or] cards, but we play other things, but not these activities.

Culturally appropriate long-term care would need to consider food, language, religious, and entertainment preferences of ethnocultural seniors. If such long-term care was in place, it would provide an additional option for caregivers who are unable to continue carrying out their caregiving responsibilities and it would allow caregivers to feel at ease if their care recipient was a patient at one of these facilities.

Participants identified many gaps in Ottawa's health care system, in terms of accessing primary care, home care, and long-term care that meet the needs of ethnocultural communities. One key informant noted that it is unpaid ethnocultural caregivers who deserve the credit for providing culturally appropriate care for their loved ones:

I think in the big spectrum of things [...] these caregivers are helping the system...they're helping to make sure that the care receivers are taking their medication on time, and following instructions, and providing them [with care] in their own language.

Thus, ethnocultural caregivers in Ottawa whose care recipients do not speak English, have a larger scope of practice compared to those with English-speaking care recipients who can communicate with paid caregivers on their own. Oftentimes, support from the community can help alleviate the challenges that caregivers face when connecting with health services.

9.3 Precarious Community Support

The third main finding of our study reveals that community support is very important for caregivers who attend community activities and events, but this support is precarious due to

unstable and unreliable funding, a volunteer workforce, and problems with transportation, and thus also in jeopardy. The majority of caregivers across ethnocultural groups discussed the importance of social and cultural activities and events that take place within their ethnocultural communities. For some, it appears to be a key factor in mitigating their social isolation. A key informant summarized a sentiment he had heard from a caregiver in the Sri Lankan community: “You know, I would have never [left] the house [...]. Why would I [...] if I didn’t have anything like this presented to us? I would have just stayed at home and watched TV.”

Different ethnocultural communities offer a variety of activities and events for seniors, allowing caregivers to socialize with each other and share their experiences. Participants frequently mentioned how getting “involved in the community” is helpful in coping with caregiver stress. In addition to reducing stress, social activities also conferred a sense of satisfaction in being part of a community. A caregiver from the focus group with the Polish community shared that participating in community events “gives you a feeling of belonging, belonging to a group.” Socializing is key to these gatherings, and “we gain courage and strength from telling our own stories” (Focus group, Chinese community). As a key informant reiterated, these activities help caregivers to “start to develop a level of confidence.” Although these community activities and events can be beneficial in terms of reducing stress, and conferring a sense of belonging, courage and strength, the community support can be precarious.

A key dimension of this precariousness is the reliance on volunteer work. Volunteer coordinators are “working day and night” (Key informant, Nepalese community) to support their community and struggle to provide direct care to their community members. Each volunteer coordinator has their own approach to coordinating community activities. One volunteer coordinator expressed his volunteer responsibilities:

...when I'm alone there I have to do everything from A to Z. Like for example, I had to search for [the] topic, and the speaker, and send invitations, organize dates, send out invitations, organize ...lunch menus, drinks, and find more volunteers, and finally on the day you have to go there and set up the room, set up sound system, and ...any projection, you know I have to set it up every night before the speaker. It's a three hour time frame and I don't want to lose any moments, any time, and that's why it's very busy.

Some volunteer coordinators expressed that their purpose was to lift the spirits of seniors and caregivers. One volunteer coordinator shared:

The goal of coming to the centre is to be happy. So I have to be very positive, to help them out, to make sure that they're happy and they are willing or, or wanting to come to the centre everyday.

On the other hand, some of the volunteer coordinators expressed that even though they are happy to support their respective communities, they are overburdened by their volunteer work. Part of the reason volunteer coordinators felt pressed for time in organizing activities was because of a lack of volunteers to share the workload. One key informant went on to say, "I wish that I could have somebody to tag along and learn the process and one day will take over or help me. But it's so hard." In addition to organizing activities and events, volunteer coordinators are also responsible for obtaining funding to facilitate community programs.

Although we did not ask any specific questions regarding funding of ethnocultural community programs during our focus groups and interviews, some key informants brought this issue to our attention as it greatly concerns them. They told us that they do not have adequate or reliable funding to run their programs. They also felt that they lack the skillset required to write the grant applications in order to secure funding for their community work from the government

or other funders. Some volunteer coordinators expressed confusion, in that they did not understand the processes of acquiring funding through grants and applications. Some communities also suggested that completing grant applications for the “New Horizons for Seniors” program is dependent on the human resources available, and some communities have greater capacity to complete applications compared to others. Some key informants highlighted that a substantial amount of the funding obtained by the SPC is used towards planning and organizing social gatherings in an attempt to help reduce social isolation. Unfortunately, without adequate or reliable funding, community support via programs, services, and activities cannot thrive and caregivers may be left isolated.

One of the components of a successful community program is the ability to bring people together. Adequate funding can help ethnocultural communities ensure their members can be transported to and from gatherings. Transportation problems were a significant barrier to community participation among caregivers. Several participants expressed their view that Ottawa is especially lacking in terms of age-friendly public transportation. Many participants told us that transportation issues influenced their willingness to travel to activities and events, even on Wednesdays, when Ottawa’s local transportation service, OCTranspo, is free to seniors. Some challenges with transportation include the lack of frequency (e.g. buses only coming once every hour) and difficulty with access (e.g. bus stops being too far away for seniors to walk). One participant explained “I’m very small, so even that big step getting onto the bus is a challenge” (Caregiver interview, Sri Lankan community). A key informant agreed and noted that:

The issue [...] is the road system, the transportation system is not friendly to seniors being by themselves. ... And they cannot take a bus, that is only going to come for another hour if they miss the bus. So our communities are not senior friendly.

Caregivers also stated that they wished the ParaTranspo system was more reliable, as currently “it’s not very practical. You can only call it at a certain time, 24 hours before and even then it’s not that reliable.” This unreliability of public transportation created a challenge for caregivers to attend community activities and events.

Interestingly, weather had an impact on the timing of community activities, as some seniors leave Canada during the harsh winter season. Also, the winter weather has an impact on the willingness of caregivers to attend community activities and events. For instance, some caregivers were unable to participate in this study due to winter weather-related mobility issues and safety concerns. According to the Chinese, Indo-Canadian, and Polish communities, the summer weather allowed for more organized activities and encouraged physical activities, such as walking and dancing.

In sum, ethnocultural community support is critical for supporting unpaid ethnocultural caregivers in their work and reducing their experience of social isolation. We found that the majority of unpaid ethnocultural caregivers are grateful and appreciative for the existing community support that is offered to them. This community support provides them with the opportunity to leave their home, interact with others from the community, and have a break from their caregiving responsibilities. Yet, this community support is precarious due to unstable and unreliable funding from funders, a volunteer workforce, and transportation issues.

10 Discussion

In collaboration with the Social Planning Council of Ottawa (SPC), this study explored the experiences of social isolation of unpaid ethnocultural caregivers who provide care to seniors in Ottawa. An investigation of this kind has not been conducted in Ottawa before, and we hope

that it is a helpful, albeit modest, contribution toward understanding the needs of ethnocultural communities in this increasingly diverse city.

Our study found that many ethnocultural caregivers in Ottawa experience a triple jeopardy shaping their experiences of caregiving and social isolation. First, caregiving is challenging, regardless of age or ethnicity; second, ethnocultural caregivers face cultural barriers that make their caregiving responsibilities more difficult; and third, community activities, which are the main source of support for ethnocultural caregivers, are precarious. Our discussion returns to the social determinants of health (SDoH) to consider each of these interrelated issues.

In considering the context of providing care in Ottawa's ethnocultural communities, some social determinants of health from the Canadian framework were analyzed in our study, including health services and social safety networks. Other SDoH frameworks, such as the World Health Organization (WHO) and American frameworks, helped us identify additional determinants of health that were not included in the Canadian framework. These determinants emerged directly from our data and included stress, culture, language, and transportation. We recognize that these are not the only social determinants of health that are relevant to the study of unpaid caregiving and ethnocultural populations. Rather, we acknowledge that other determinants, including, housing, race, immigration status, income, and gender are highly applicable to our study, but our student team did not have the advanced skills or training to be able to carry out such an analysis.

10.1 Caregiving Is Challenging

Based on our research and prior literature, we speculate that social isolation among ethnocultural caregivers arises in part due to the challenges of care work. The quantitative

results, which revealed no statistically significant differences in caregivers' self-reported isolation or loneliness across ethnic groups, contributes to the first jeopardy.

In the General Social Survey (GSS) data, levels of social isolation among ethnocultural groups were more similar to the levels reported among Canadian, British, and European groups, than had been expected. This could be due to ethnocultural respondents lacking recognition of themselves as 'caregivers,' which could have impacted how they answered the GSS survey questions related to isolation and loneliness. It should be noted, however, that it is unknown whether a lack of self-identification with the title of 'caregiver' is unique to ethnocultural populations, or whether it may be common among caregivers regardless of ethnocultural background.

According to the literature, the 'caregiver' social identity may go unrecognized by some caregivers because other social roles take precedence in their life (Hughes, Locock, & Ziebland, 2013). For example, our field observations from the focus group discussions showed that participants identified themselves in terms of their familial relationship to their care recipient, such as a wife, husband, daughter, or son before any other relationship, and thus, did not necessarily perceive themselves as caregivers (Hughes et al., 2013). We speculate that caregivers may not view caregiving responsibilities separately from their primary identity as a family member. Further, they may be so habituated to providing care in their daily life over many months or years, that it becomes their norm and thus do not self-identify as a 'caregiver'.

While some focus group and interview participants did not explicitly self-identify as 'caregivers,' the responsibilities they described as part of their daily life are reported in the literature as caregiving tasks. These activities fall into two broad categories: Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Weldeslassie, 2008).

Caregiver participants mentioned several ADLs they assisted with, including helping their loved one get into and out of bed, using the toilet, bathing, and eating (CIHI, 2010). Similar to those IADLs mentioned in prior research (Dickerson, Reistetter, & Gaudy, 2013; Gillespie, Mullan, & Harrison, 2013), caregivers in our study helped their loved ones by preparing meals, performing housework, managing medication, providing and arranging for transportation and accompanying their loved one to medical appointments. Participants did not mention any caregiving activities that have not already been identified in the literature.

We found that stress was a key determinant influencing the lives of the caregivers in our study. While stress does not appear as one of the 14 social determinants of health in the Canadian framework, we suggest that it would be a helpful determinant of health to consider for this population, especially since it prominently appeared in the qualitative data. Stress can contribute to feelings of anxiety, depression, and fatigue in caregivers (Cannuscio et al., 2004; Carretero, Garcés, Ródenas, & Sanjose, 2009; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Sawatzky & Fowler-Kerry, 2003). There are many possible sources of caregiver stress, including difficulty maintaining a healthy balance between work, family, and caregiving (Crooks & Williams, 2008). Many of our participants expressed feeling tired, stressed, and overwhelmed as a result of this imbalance, as they found themselves adjusting their personal schedules to meet the needs of their care recipients, including having to take a leave of absence from work. They also shared feeling stressed about having to provide care by themselves, especially when support may be less accessible, for example in the middle of the night when they felt they could not call a neighbour for help.

One of the underlying issues that arose directly from our analysis was the difficulty caregivers experience in navigating the health care system. Health services, an important social

determinant of health for our population, was prominent in our findings, particularly in terms of access. Caregivers discussed difficulty navigating the health care system in three main ways: wait times, accessing home care, and obtaining respite.

First, caregivers reported feeling frustrated about the long wait times they and their care recipient had to endure in order to access various health services. Some caregivers had to repeatedly demand services for their loved one before gaining access, and by the time a health professional was available to see their loved one, the crisis was sometimes already over. Wait times is an issue in acute care settings, but also in terms of home care. In 2010, a reported 10,000 Ontarians were awaiting access to home care services (Ontario Health Coalition, 2011). Caregivers expressed the experience of waiting for care as highly stressful and tiresome, which confirms the literature's finding that the inability to access the right care, at the right time, directly influences the stress levels of caregivers (Liddy et al., 2016). Difficulty accessing home care is a common experience, rather than one necessarily rooted in culture.

Second, caregivers across focus groups and ethnocultural communities had difficulty acquiring adequate home care services. While not all caregivers explicitly expressed a need for more home care support, some instead articulated a need for more respite care and caregiver training. Others shared that even when care is accessed, they did not necessarily feel that it adequately relieved their workload as caregivers. We speculate that a desire for respite and training is related to being overburdened and needing more home support. *The Long-Term Care Act, 1994*, mandates that Ontarians who provide care in the home are to be supported in their responsibilities (MOHLTC, 1994), and one way in which the provincial government can support caregivers is by providing necessary home care services to care recipients.

The Community Care Access Centres (CCACs) were developed to provide home and community care across the province (Day, 2014; OACCAC, 2014); however, due to high costs and fragmented care, they are now in the midst of being dismantled over the summer of 2017 (Porter, 2017). The MOHLTC has stated that by dissolving the CCACs, and the extra layer of administration, the LHINs will be better equipped to provide home care (Porter, 2017). The \$10.7 million savings from the CCACs' upper management salaries is planned to be redirected toward patient care (Porter, 2017), and will hopefully provide more respite relief to unpaid caregivers.

Third, participants described needing respite relief due to the limited service their care recipient received. This sense of minimal support is unsurprising as the CCACs have experienced a 101% increase in the number of home care patients served in the last decade, while the funding allotted to this system increased by less than a quarter of a percent during the same time frame (OACCAC, 2014). In an attempt to balance the disproportionate funding and influx of patients, the services available to care recipients has been restricted and thus, the respite needs of caregivers often go unaddressed.

Caregivers who participated in this study expressed a desire to receive some form of formal caregiving training. This could be the result of task-shifting in the Ontario home care system. Since caregivers are required to carry out more care work due to limited hours of home care support (Ontario Health Coalition, 2015), some of our participants felt unable to perform the demanding and/or complex tasks that inevitably fall to them. Other caregivers were worried about what would happen if their loved one's care needs intensified and they could no longer perform the required caregiving duties.

Caregivers may experience feelings of inadequacy because they are required to take on more demanding and/or complex caregiving tasks than they are prepared to perform, and they are required to do so without adequate professional support. This can be explained by the cost-saving phenomenon known as “task-shifting” (Barken et al., 2015). Some of the Ontarian home care literature states that task-shifting most commonly occurs between regulated nurses and unregulated personal support workers (Barken et al., 2015; Zeytinoglu, Denton, & Brookman, 2014). However, our analysis confirms another literature finding that tasks once conducted by personal support workers and nurses now fall to unpaid caregivers to perform, often with little or no assistance or training (Clemmer et al., 2008). Some caregivers expressed frustration with the CCAC as they were unable to provide support with complex caregiving tasks, and often caregivers felt that this was a result of budget cutting. This home care system shortcoming is deemed to be the result of the previous tendering model of “competitive bidding” (Ontario Health Coalition, 2015); however, as of 2012, this system is no longer in place (OACCAC, 2014). The fragmentation and insufficient support that is left behind from “competitive bidding”, as expressed by our participants and confirmed by the literature, must be addressed through increased funding and better administrative processes.

As Ontario’s senior population continues to grow (The Ontario Seniors’ Secretariat, 2013), the responsibility of providing care will remain on the shoulders of family members and friends. Therefore, supporting caregivers will become a larger and more complex challenge. This first jeopardy asserts that caregiving is hard for everyone, that it is stressful, frustrating, and increasingly demanding, as the scope of home care shrinks and caregivers are forced to pick up the pieces. Yet, our study found that ethnocultural caregivers may face additional challenges.

10.2 Ethnocultural Caregivers Face Additional Challenges Due to Cultural Barriers

Our qualitative data suggests that ethnocultural caregivers experience cultural barriers in primary care, home care, and long-term care, which create added challenges for them in performing their care work. Caregivers shared two underlying cultural barriers that make their work harder: lack of interpretation support and lack of cultural sensitivity, particularly in long-term care.

Caregivers from ethnocultural communities often have to act as interpreters when their loved ones do not speak English, which expands the scope of their responsibilities and demands more of their time and resources. Participants shared that interpretation is a major part of their caregiving responsibilities because interpretation services are lacking in health care settings, including primary care and home care. This is consistent with sources that state that Canada lacks health care interpretation services due to limited national standards (Silversides & Laupacis, 2013).

Unpaid ethnocultural caregivers in Ottawa work tirelessly to meet the cultural and language needs of their care recipient as a result of systemic barriers that deprive seniors of culturally appropriate health care. Through our focus groups, we found that home care nurses and personal support workers were often unable to communicate with non-English speaking care recipients in their native tongue. When care recipients cannot communicate with their health professionals, ethnocultural caregivers are obliged to interpret for their loved ones, or to troubleshoot when care is not culturally appropriate. Home care typically presents an opportunity for caregivers to take a break and attend to other tasks, including visiting with friends or other family members, or attending a community activity. However, ethnocultural caregivers who have to serve as interpreters for their loved ones may not benefit from this much-needed respite. We

speculate that the inability to take advantage of these brief moments of reprieve could leave ethnocultural caregivers more socially isolated than those for whom home care offers a break from caregiving duties.

It is evident that culture and language are important social determinants of health, as culture and language barriers can negatively impact caregivers' self-reported health (Ng, Pottie, & Spitzer, 2011), and can alienate them from the health care system (Kalich, Heinemann, & Ghahari, 2016). Our qualitative findings confirm prior research, which demonstrates that people from ethnocultural communities in Canada often experience health inequities due to language barriers (Khan & Kobayashi, 2015). Although absent from the Canadian SDoH framework, our findings suggest that culture and language should be considered in relation to unpaid ethnocultural caregivers in Ottawa, and should be included in the Canadian framework.

A lack of cultural sensitivity in long-term care is a second major barrier for ethnocultural caregivers, and could impact their experience of social isolation. We learned anecdotally that Ottawa does not provide culturally-specific long-term care options. This may have ramifications for ethnocultural seniors who do enter long-term care homes that are not culturally sensitive; we speculate that it may be difficult for them to maintain a sense of social identity in a setting that does not provide culturally appropriate care in terms of one's spiritual/religious, language and food needs. The lack of culturally sensitive long-term care options in Ottawa also has implications for those who do not enter institutional care as a result. These care recipients may not feel open to moving or able to move into long-term care when it is no longer feasible for them to be cared for in the home, potentially putting further pressure on their caregivers to continue to provide care long after caregivers are physically, mentally or emotionally fit to do so. Ethnocultural caregivers may also resist allowing their loved ones to move into a long-term care

home that does not cater to cultural needs, even when they face difficulties in continuing to provide unpaid care at home.

If culturally appropriate long-term care options were available in Ottawa, perhaps seniors would have a better chance of maintaining their social networks within the city, instead of moving outside of Ottawa to find culturally appropriate long-term care homes, as was the case for the Polish community. This finding is important, as previous research demonstrates that language and cultural barriers to care may be associated with increased loneliness or isolation (Carstairs & Keon, 2009; De Jong Gierveld et al., 2015). In other words, funding culturally appropriate long-term care options could reduce the social isolation of ethnocultural seniors, and provide alternatives for ethnocultural caregivers who are unwilling or unable to provide care in the home.

The *Long-Term Care Act, 1994* mandates that recognition be given to the importance of providing health services that align with the cultural and language needs of all Ontarians (MOHLTC, 1994). However, our analysis concludes that culturally appropriate long-term care is lacking in Ottawa. This is further confirmed by the Champlain LHIN's *Developing the Integrated Health Service Plan 2016- 19: Community Engagement Report*, which states that “greater emphasis needs to be made to offer culturally and linguistically appropriate services across the regions” (2016, p.17). The ramifications of not providing culturally appropriate long-term care options are that ethnocultural seniors may lose the ability to choose where to age, as they are forced to remain at home under the responsibility of their unpaid caregiver (Wiles et al., 2011). These gaps in services have implications for ethnocultural communities, as greater numbers of people from diverse backgrounds will demand culturally appropriate services and resources. While some caregiver needs will not be able to be met by community programs, many

individuals will find support in their ethnocultural communities. Thus, the need for sustainable community programs becomes increasingly important for ethnocultural caregivers.

10.3 Precarious Community Support

The final jeopardy is that the community support that ethnocultural caregivers rely upon is precarious. The minimization of the role and scope of the Ontario government in providing welfare for seniors has shifted the responsibility for care from the state to unpaid caregivers (Clemmer et al., 2008). Our study found that when ethnocultural caregivers become overwhelmed with care work, which many inevitably do, the community becomes the impromptu social safety net for caregivers. The social safety network is a social determinant of health in the Canadian framework, and consists of the “range of benefits, programs, and supports that protect citizens during various life changes that can affect their health,” (Mikkonen & Raphael, 2010, p.36) including, for instance, the life transition of becoming a caregiver for a senior. Ethnocultural caregivers in our study highlighted the importance of community activities in sustaining their social and emotional health during this life transition. The literature explains that social support, or “support accessible to an individual through social ties to other individuals, groups, and the larger community” (Lin, Ensel, Simeone, & Kuo, 1979, p.109), can relieve anxiety and enhance well-being (Chin & Noor, 2014; Karademas, 2006; van der Horst & Coffé, 2012), which confirms the perspective of ethnocultural caregivers in our study.

Our participants described how they receive a wide range of benefits from their communities, including, for example, social interaction, health information, interpretation assistance, and emotional support. These forms of assistance appear to be protective of caregiver health, which can be threatened by the tasks and responsibilities involved in care work. According to caregivers in our study, the community is essential in terms of providing spaces

and opportunities for social connection with other people who are also caregiving. As such, ethnocultural community support in Ottawa appears to be a key factor in mitigating caregivers' experience of social isolation.

As important as community programming is in meeting the social and practical needs of caregivers in Ottawa, programs are precarious if the following three essential components are not in place: access to meeting spaces, availability of volunteer coordinators to organize activities, and reliability of transportation to get to and from events. These three components depend upon adequate funding, without which programs become unsustainable and risk being interrupted or stopping altogether. Our study found that since these components are unstable, they constitute three underlying issues that contribute to the precariousness of community support.

The first underlying issue raised by participants in our study is the lack of accessibility to affordable community spaces in Ottawa. Some participants referred to particular community centres where their community meets consistently for activities, while volunteer coordinators shared their struggle to afford spaces for community activities in City of Ottawa buildings. Key informants revealed that sometimes volunteer coordinators create excellent programs that can be dismantled simply because rental fees for community centres are too expensive.

In theory, under the guidance of the *Ottawa Older Adult Plan*, the City of Ottawa is mandated to provide accessible and affordable spaces for recreational activities for socially isolated seniors (City of Ottawa, 2015). The *Plan's* first priority aims to “improve access to City buildings” and to “encourage the application of age-friendly principles in the community,” while its fifth priority is to “encourage participation of low income and socially isolated older adults in cultural, recreational, and leisure pursuits” (City of Ottawa, 2015). In reality, these positive intentions do not seem to be prioritized in practice; the *Plan* includes no action items that aim to

make community spaces more affordable. Without access to low-cost space, it is difficult for volunteer coordinators to provide much-needed activities in these communities. According to our study, the Ottawa municipal government does not seem to be upholding its goals of making City buildings more accessible, applying age-friendly principles, and enabling low-income seniors to engage in community activities. Volunteer coordinators voiced their frustrations with this financial barrier, which complicates their ability to offer community activities. If the City allows unaffordable rental fees to persist, it may hinder the municipal government from reaching its own goal of supporting isolated seniors in the community.

Ethnocultural groups offering social programs are dependent upon policies that support them, and therefore, policies that block volunteer coordinators from carrying out their activities are not abiding by the city's *Older Adult Action Plan* (City of Ottawa, 2015). With more stable and adequate funding, and affordable rental fees for city-operated community centres, volunteer coordinators could continue their great work in community spaces and continue to address the social needs of their community members. The federal government's "New Horizons for Seniors" program provides the SPC with grants of up to \$25,000 for projects that help involve seniors in community life and reduce the risk of social isolation (Carstairs & Keon, 2009). More sustainable funding for activities would also better support a currently precarious labour market of immigrants who organize and carry out community activities. The second underlying issue is that most of the coordinators who are building and offering programs to ethnocultural seniors are doing so as volunteers without payment. Yet, it is challenging to retain workers long-term in roles that provide no income, job security or stability for their families. We learned anecdotally that many volunteer coordinators are highly educated, with professional degrees from their countries of origin, but are unable to find steady work in Ottawa. Job insecurity leaves them

financially vulnerable, provides their communities with an unstable volunteer base, and leaves community programs in a constant state of precariousness.

Several key informants were unable to find employment in Ottawa, despite having postgraduate and professional degrees from their country of origin. This issue is part of a broader social problem of “precarious employment,” in which immigrants across Canada are unable to attain permanent employment with decent wage and health benefits, and instead have to accept temporary low-paying positions with few, if any, benefits (Lewchuk & Laflèche, 2014, p.45). We also learned that some volunteer coordinators work multiple jobs for which they are overqualified and others cannot find work at all. We speculate that Ottawa’s health care system could become more culturally sensitive if the barriers were removed to allow more individuals from ethnocultural communities, who have backgrounds in social work and health from their countries of origin, to enter the labour market.

Volunteer coordinators demonstrated admirable levels of commitment to their volunteer work, many working long hours, including on weekends and evenings. Many ethnocultural community programs for seniors and caregivers in Ottawa are insecure due to a lack of funding to retain volunteer coordinators. Since the workforce is volunteer-based and access to space is unstable, the entire infrastructure to support community programming for seniors and caregivers is highly precarious. Yet, even if these two components of space and human resources were secured, community events will fail if no one shows up, hence, the importance of transportation.

An age-friendly Ottawa is a dream for many caregivers, which includes accessible and reliable transportation. This constitutes the third underlying issue; transportation is a social determinant of health that is not listed in the Canadian SDoH framework, but was found to be a major factor influencing whether or not caregivers attended community activities and events.

Some communities carpool to events, and in these cases the main issue is the reimbursement of volunteer drivers. For other communities who rely on public transportation for caregivers to get to events, OTranspo could be made more affordable, timely and reliable for them. Some groups discussed having to schedule all of their events on Wednesdays, because that is the day seniors can ride the bus for free. Regardless, if the weather is bad, the event has to be cancelled, indicating that caregivers may not be able to attend a community social event for at least two weeks. It is also known that for some people these community events are the only activity that gets them out of the home, so a cancelled event due to weather or a perceived lack of reliability on transportation to get there, could increase their experience of social isolation. Perhaps more frequent bus services for seniors that are free, or community programs that support alternative means of transportation (e.g. carpooling, taxi, or bus rental) would allow caregivers to travel more efficiently and allow them to attend community activities and events. The Canadian SDoH framework could be enhanced by including transportation, which is not only relevant to our population of interest, but to the Ottawa context at large. Ethnocultural caregivers in Ottawa often rely on their communities for support, but the infrastructure needed to maintain this informal support is unstable and subject to failure at any moment, leaving caregivers in a vulnerable state.

The current ethnocultural community programs provide a lot of support to their communities. However, these community programs warrant an increase in funding to support community programs that enable healthy ‘aging in place’ in Ontario (The Ontario Seniors’ Secretariat, 2013). Further, this research indicates that unreliable transportation and harsh winter weather conditions in Ottawa are barriers in accessing community support programs. This finding may be of key importance to city officials, as community programs are essential to

maintaining social support and preventing social isolation but they may be limited due to available and reliable transportation.

In recognizing the need for sustainable policies and programs, the City of Ottawa's *Older Adult Action Plan* indicates that there needs to be "respect and inclusion of older adults in its service delivery" which can promote "opportunities for active living, lifelong learning, and community participation in convenient and responsive environments" (City of Ottawa, 2015). Therefore, having policies with an 'aging in place' priority that cater to the needs of seniors and caregivers together can decrease stress levels. In ethnocultural communities, the stress on community programs can be acute when they do not have sufficient funding and resources to meet the growing needs of their populations. If community programs in Ottawa cannot sustain the demands of their caregivers, the level of stress for this population could contribute to a decreased health status.

In sum, it is important to evaluate the precariousness of ethnocultural community support programs in Ottawa, which are vital to supporting Ottawa's ethnocultural unpaid caregivers, in terms of the three underlying issues of unaffordable community spaces, unsustainable volunteer workforce, and unreliable transportation, so that communities can continue to conduct their important work to reduce the social isolation of ethnocultural caregivers.

This research provides a good foundation for future investigations into the relationships between caregiving responsibilities and gender, age, race, and multigenerational homes. Future research should also consider applying gender-based analysis to fully understand the differences in caregiver isolation between women and men, and to develop evidence-based home care policies (Morris, 2004).

11 Limitations

For the quantitative section of the study, we reviewed the GSS Study Documentation file to understand why 1,037 of the 2,470 participants were not asked the following question:

“During the last 12 months, have your caregiving responsibilities caused you to feel lonely or isolated”. In order for participants to answer this question, caregivers must have met the following criteria:

1. They answered the survey questions themselves and not by proxy;
2. They provided an answer between 1 and 60 to the question: “During the past 12 months, how many family members, friends or neighbours have you helped with any of the previous activities”; and,
3. They provided an answer between 1 and 168 to the question: “In an average week, [list the] number of hours of care or help provided by the respondent with these activities.”

If the survey respondent did not satisfy any of the above criteria, they would not have had the opportunity to answer the question about whether they felt lonely or isolated. This is important because we know that some caregivers were screened out of the question about whether they felt lonely or isolated; for instance, 502 participants were screened out because they responded “I don’t know” to the statement: “In an average week, [list the] number of hours of care or help provided by the respondent with these activities.” As such, it is possible that many caregivers were not asked whether they felt lonely or isolated simply due to a mistake, withholding of an answer, a lack of awareness about their caregiving responsibilities, or, notably, a lack of understanding of the question due to a language barrier. As a result, caregiver loneliness or isolation may be underreported in the GSS.

Bias may also have occurred in the quantitative section of the study when the research team regrouped 25 ethnicities into 5 broader ethnic categories. This approach was intended to account for the low response rate recorded by the GSS in some of the 25 ethnic communities and to make statistical comparisons across groups possible. However, regrouping by ethnicity could have discounted possible differences between ethnocultural groups. As well, it is important to note that in the survey, the GSS variable of primary interest in our study combined the terms “lonely” and “isolated,” and therefore we were not able to distinguish between experiences of loneliness and isolation.

Recall bias may also have occurred in both quantitative and qualitative sections of this research study. For instance, the GSS requested participants to identify their experiences over the past 12 months. Since some participants may have faced a language barrier, or difficulty simply remembering specific experiences, their responses might not have been accurately captured. For the qualitative data collection, the researchers noted that participants might have responded in socially desirable ways, as they were inclined to elaborate on their life stories depending on how the other participants were responding to the focus group questions. However, the research team was trained on how to steer participants in the right direction with probing questions and in ensuring that each question was answered completely and in response to the purpose of the question.

Our qualitative methodology has further limitations that are important to discuss. Focus group facilitators do not always conform to the social norms of participants, potentially silencing their ability to fully express themselves (Bowling & Ebrahim, 2005). Training is helpful to ensure that the facilitator creates a comfortable space for participants and builds rapport before the focus group discussion begins; yet, it is difficult to know to what degree feelings or

comments were withheld due to the contrast in social norms between the facilitator and the participants (Bowling & Ebrahim, 2005). The limitations for this study have been described in further detail below.

Selection bias occurred during the recruitment phase for the qualitative section of the study. Since the community partner facilitated recruitment of participants, the research could only capture participants/communities that were part of the Social Planning Council of Ottawa's (SPC) network. As such, the research does not capture the experiences of caregivers from all ethnocultural communities in Ottawa. Some ethnocultural communities that are a part of the SPC were also unable to participate in the study as some volunteer coordinators could not find participants interested in the study, and found the participant recruitment period to be conflicting with ethnocultural festivals and celebrations. Some focus groups could not be held due to weather conditions that prevented participants to travel to their community gathering. The researchers made every effort to reach out to those communities who were unable to organize or host a focus group in their community space, for example, by offering to conduct individual interviews at locations convenient for participants.

This research involved the use of interpreters to facilitate some of the focus group discussions that were held in languages other than English. As such, our focus group script and questions were interpreted, rephrased, and then clarified by interpreters who were not associated with the research team and were not fully trained on how to facilitate focus group discussions. Further, the definition around what constitutes a "caregiver" may have been misinterpreted by some ethnocultural communities. As reported above, this misinterpretation can be associated with participants not identifying themselves as a caregiver due to ethnocultural norms. To overcome this bias, the researchers circulated a research poster to the SPC, summarizing

eligibility criteria and emphasizing who is considered a caregiver, so that potential participants could identify themselves.

The focus groups that were not conducted in English were transcribed by individuals who were fluent in the participants' language. During transcription, discrepancies were observed between what the research team had intended to ask the participants and how the focus group interpreters had reworded the question(s). Overall, these discrepancies were handled with care during the coding phase of the study to ensure consistency in data interpretation and analysis.

Due to the nature of the qualitative section of the study, some participants may not have felt comfortable sharing their experiences with other members of their community who were present at the focus group session. However, the research team was trained on how to build rapport with participants prior to commencing the focus group discussion and ensured that all participants were aware of their rights as a participant.

12 Conclusion

This study explored whether and how unpaid caregivers who provide care to seniors experience social isolation, with a specific focus on caregivers from various ethnocultural communities in Ottawa. This study adds to the body of literature that suggests key challenges for unpaid caregivers include stress, work/life balance, navigating the health care system, and communicating with health professionals. Although caregiving is difficult for all unpaid caregivers, it is increasingly difficult for those from ethnocultural communities who often face additional challenges, particularly cultural and language barriers. This study contributes to prior research which suggests that cultural and language barriers exist alongside social isolation or loneliness. While community support has proven to be essential to the health and well-being of unpaid caregivers, this social support network for caregivers is precarious due to unstable

government funding and support, a volunteer workforce, and unreliable public transportation. As the city of Ottawa (as well as other levels of government) continues to push for ‘aging in place,’ future studies may do well to address the impact that this policy places on unpaid caregivers, especially those from ethnocultural communities who face additional barriers.

13 Knowledge Dissemination

The Canadian Institutes of Health Research (CIHR) has developed the *Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches* (CIHR, 2012), which will be used to inform our knowledge translation plan.

As part of a community-based participatory research approach, our community partner, the Social Planning Council of Ottawa (SPC), has been actively involved in all phases of the research process: developing the research question, selecting the appropriate methodology, data collection, and dissemination of the results (CIHR, 2012). This study has used an Integrated Knowledge Translation (iKT) approach (CIHR, 2012), in that the SPC has been involved throughout the entire research process and is also the main knowledge user of this study. Although this study has utilized the iKT approach, it is also essential to develop an end-of-study knowledge translation plan as most of our knowledge dissemination activities will occur upon study completion (CIHR, 2012). Below we describe our end-of-study knowledge translation plan, which includes key knowledge dissemination activities.

- 1) **Health: Science, Technology and Policy Research Day** – On April 10th, 2017, the research team gave a 20-minute oral presentation, with PowerPoint slides, at Carleton University to share the results of the study with professors, students, and community stakeholders.

- 2) **Infographic** – The research team has developed an infographic (see Appendix F) to be shared with the SPC for further dissemination. The purpose of this infographic is to communicate the main findings of our study in plain language. The research team will share this infographic, along with the final report, to all study participants who have expressed interest during the data collection phase and who have provided their contact information on the consent form.
- 3) **End-of-Study Community Partner Meeting** – The research team presented the findings of the study to the SPC on April 12, 2017. This meeting provided the research team with an opportunity to share lessons learned and plan for future knowledge dissemination activities within the SPC’s stakeholder network.
- 4) **Social Planning Council of Ottawa Stakeholder Meeting** – Based upon the discussions and plans made at the end-of-study community partner meeting, members of the research team will present a PowerPoint presentation at the SPC’s Annual General Meeting on May 24, 2017. The infographic mentioned above will be shared with attendees. The objectives of this meeting will be to: (1) inform the greater stakeholder community on the findings of this study and (2) discuss next steps to secure future funding for caregiver and senior programming.
- 5) **“Carleton Connects: Building and Celebrating Community Partnerships” Conference** – The research team has submitted an application to present a poster at the “Carleton Connects: Building and Celebrating Community Partnerships” conference taking place at Carleton University from October 13-15, 2017. This conference will allow the research team to share the findings from this study and network with others to share knowledge about community-based partnerships and projects.

- 6) **Journal Publication** – The research team proposes to publish a journal article on the key findings of this study to target an academic audience. The purpose of this is to spark interest among other researchers on this particular topic, and provide a stepping stone for continued research in this area. We are particularly interested in publishing an article in one of the following journals: Canadian Journal on Aging, Aging and Mental Health, Journal of Cross-Cultural Gerontology, The Gerontologist, Journal of Aging and Health, Journal of Applied Gerontology, or the Journal of Family Nursing.

14 Contributions

As a group, we agree that everyone has contributed substantially to this project. While we cannot list every single task completed during this project, this section highlights some of the major contributions.

In August 2016, all students were introduced to the lead coordinator of the Social Planning Council of Ottawa (SPC), Sybil Braganza, and we collectively decided on a topic for our study. All students equally provided input on the ethics application, the development of appendices for focus groups and interviews, and a recruitment poster. The SPC aided in the distribution of the recruitment poster to raise awareness about our study and seek help from volunteer coordinators from the Creating Community for Isolated Ethnocultural Seniors group to recruit participants for our study. Before commencing the data collection phase, all students received a 3-hour focus group training by supervisor Susan Braedley.

The majority of the communication and engagement between the students and the SPC was carried out by Laura O'Dell. Laura attended several community meetings, events, and conferences in which she had the opportunity to network with others and report on the progress of our study. On occasion, she was also accompanied by Claire Pilon-Robertson and Hayley

Miloff.

Natalie Fersht was the lead on all internal communications between students and supervisors. Natalie was responsible for drafting e-mails, developing meeting agendas, writing up meeting minutes, and creating monthly progress reports to ensure that the research team was on track.

Planning and scheduling focus groups and interviews was completed by all group members. All students were involved in at least one focus group discussion and two interviews as either the lead facilitator or note taker, and provided refreshments as required.

Statistical data analysis of the General Social Survey (GSS) and National Household Survey (NHS) results was conducted by Laura O'Dell. Laura was responsible for conducting inferential statistics, as well as developing a visible minority map of Ottawa (Appendix A), while Mehreen Anjum was responsible for generating descriptive data. Laura and Mehreen contributed to writing the quantitative results and creating tables for the final report. All group members were involved in coding the qualitative data and analyzing the findings from the focus groups and interviews. Mehreen Anjum, Natalie Fersht, and Hayley Miloff were responsible for achieving inter-rater reliability on all 13 transcripts by running coding comparison queries in NVivo and solving conflicts between different coders.

The background research and literature review was largely carried out by Hayley Miloff and Claire Pilon-Robertson, and supported by Natalie Fersht. Mehreen Anjum was responsible for writing the quantitative and qualitative methods section of the paper. All students were involved in writing the results and discussion sections. Natalie Fersht, Hayley Miloff and Claire Pilon-Robertson were involved in editing and formatting all sections of the final paper. Claire Pilon-Robertson developed the final PowerPoint presentation and knowledge

dissemination activities, including constructing an infographic pertaining to our study.

15 Appendices

15.1 Appendix A – Visible Minority Index (Ottawa)

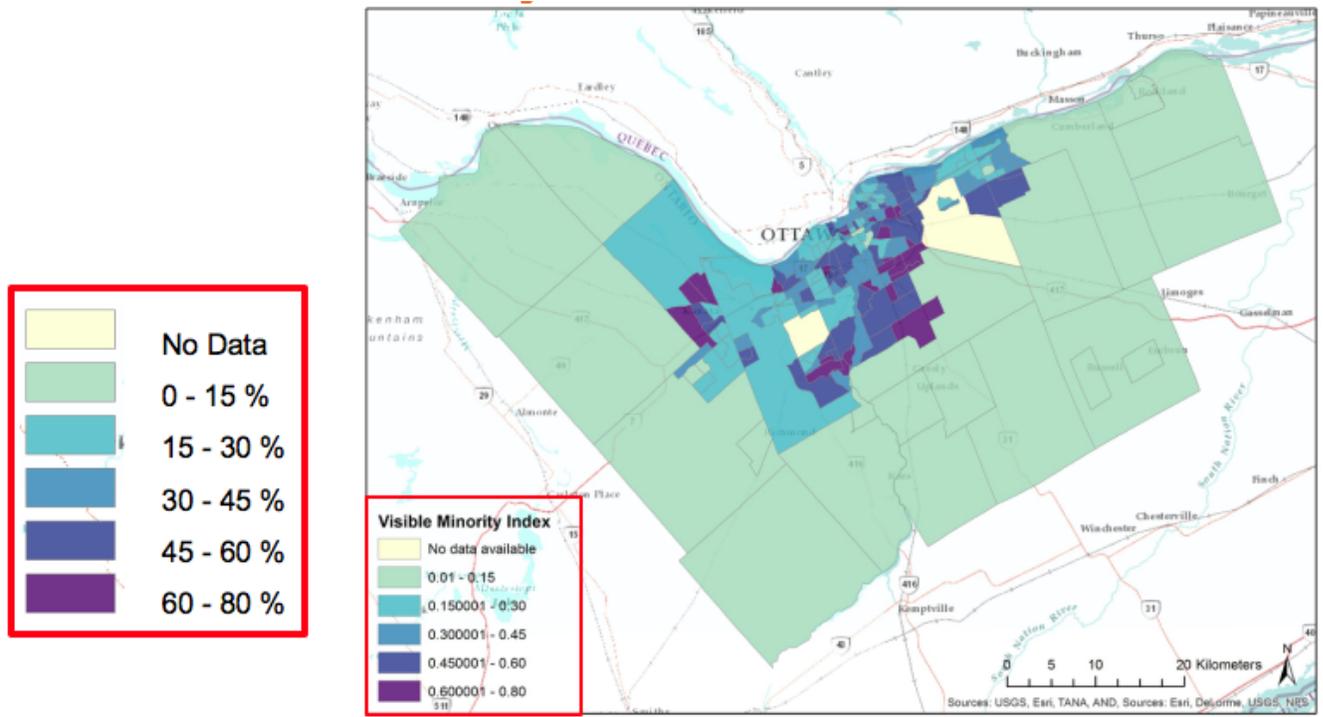


Figure 1: Visible Minority Distribution in Ottawa (Statistics Canada, 2011)

This map provides a visual representation of Ottawa's visible minority populations, using data from the 2011 National Household Survey (NHS) and ArcGIS software. The darker boxes illustrate the more diverse sections of Ottawa; much of the core of the city is in dark blue and purple, demonstrating the importance of learning how to support ethnocultural communities in Ottawa.

Since the General Social Survey (GSS) did not have data available at the municipal level, the 2011 NHS Profile Files were used to examine the distribution of ethnocultural Canadians living in Ottawa. The 2011 NHS (Statistics Canada, 2011) provides the most recent publicly

available data. The dataset on census tracts (CT) for visible minorities was extracted from the Canadian Census Analysis website, which is hosted by the Computing in the Humanities and Social Sciences (CHASS) database at the University of Toronto.

According to Statistics Canada (2015b), a CT is a limited geographic area that has a population between 2,500 and 8,000. CT's are only created for metropolitan areas that have a minimum core population of 50,000 (Statistics Canada, 2015b).

To determine the Visible Minority Index (VMI), a validated method was used in order to calculate a ratio of ethnicity based on the percentage of ethnicity in each CT (U.S. Census Bureau, 2000).

The VMI indicates the proportion of visible minorities compared to non-visible minorities in the form of an index number that represents the percentage of the population within that CT that is a visible minority. For example, an index of 0.30 would identify a CT in which 30% of the population was a visible minority. The method includes four steps conducted in MS Excel: (1) the percentage of each VM within each CT is calculated and represented as a decimal less than one; (2) each VM is then squared; (3) the sum of the squares is calculated for each CT; and, (4) the sum of the squares is subtracted from 1. This answer gives the VM index number for each respective CT.

In order to plot the VMI on a map, the geospatial data shapefile for CTs in the Ottawa-Gatineau was downloaded. A shapefile is a file format that stores information over a geometric location (ArcMap, 2017). Since this study focuses exclusively on the Ottawa region, those geographical areas belonging to Gatineau were deselected.

Initially, the VMI number for each respective CT was imported into ArcGIS in order to connect it with the CT shapefile. However, ArcGIS deleted the decimal places for the VMI. As a

solution, the VMI was imported into QGIS, an alternative to ArcGIS that allowed the complete matching with the CT shapefile of Ottawa. By associating the CT identification numbers to the shapefile, QGIS left the VMI decimal places intact. The VMI data and the CT shapefile was then transferred to ArcGIS to create the VMI map of Ottawa. To determine an appropriate colour coding scheme, we relied on ColorBrewer 2.0, an application used by cartographers to represent increasing variables using colour hues or shades (Brewer & Harrower, 2017).

To ensure the rigor of the analysis and creation of the VMI distribution map, Rebecca Bartlett, GIS and Digital Librarian for Carleton University's Maps, Data and Government Information Centre and a professional cartographer was consulted.

15.2 Appendix B – Recruitment Poster



Reducing Social Isolation for Seniors who are Caregivers

We are seeking your help with a research project **on reducing social isolation for seniors who are caregivers from ethno-cultural communities in Ottawa.**

The project will involve your help in organizing participation in one focus group for your community. Individual interviews are available as an alternative for those who are not able or willing to attend the focus group.

A “caregiver” includes any person who provides regular care to another person who is also an older adult. English is helpful but not required. The project focuses on older caregivers who are providing care to older family members – a spouse, parent, sibling or other relative – or to a friend or companion. The care can be continuous, daily, weekly or occasionally. The person who is cared for can live with the caregiver or elsewhere.

Aim: The purpose of this study is to collect the stories and experiences of caregivers from ethno-cultural communities in Ottawa, to better understand their needs and how best to reduce their social isolation and that of the people they care for. The results will be shared with the ethno-cultural communities that participate, as well as many stakeholder groups, such as Age-Friendly Ottawa. The aim is to assist communities to secure future funding for caregiver and senior programs that reduce isolation.

Project Team: This research project is being conducted as a collaboration between Masters of Health students and professors at Carleton University and the Social Planning Council.

Please help us spread the word about this research project!

The proposed project has been approved by the Carleton University Research Ethics Board-B (Clearance #106090).

15.3 Appendix C – Invitation Letter for Key Informants



Understanding Social Isolation and its Relationship with Care Provision for Older Adults in Ethnocultural Communities in Ottawa

A research project in the MSc Health Science Program at Carleton University
CUREB-B Clearance #106090

Supervisors: Renate Ysseldyk, PhD and Susan Braedley, MSW PhD

Student Researchers: Mehreen Anjum, Natalie Fersht, Hayley Miloff, Laura Cruise-O'Dell, and Claire Pilon-Robertson

Purpose: The aim of this study is to identify the key factors associated with social isolation of unpaid informal caregivers who care for seniors (65+), as well as the differences in experiences of social isolation among caregivers from different ethnocultural communities. These informal caregivers may experience distinct barriers to resources that affect their social and their care responsibilities. The study aims to contribute to policies and programs that can better support these caregivers.

Primary Research Question: Are there differences in experiences of social isolation among informal caregivers providing care to seniors from various ethnocultural communities in Ottawa?

The Study:

This research project has three components:

1) *Quantitative analysis of the Canadian General Social Survey:* This will provide a deeper understanding of the level of social isolation of caregivers from ethnocultural communities in Canada.

2) *Qualitative community research:* Focus groups with members of at least six different ethnocultural communities will be held, taking 1.5 hours each. These focus groups will provide an opportunity for caregivers to share their experiences, and the joys and/or challenges of providing/receiving care. The focus group discussions will be held in locations that are convenient and familiar to participants. If required, a translator and/or interpreter will be present at the focus group sessions. Refreshments will be provided. Interviews will also be held as an alternative for any caregivers who are interested in participating, but are unable or unwilling to attend a focus group session.

3) *Key Informant Interviews:* To better understand the context in which caregiving occurs in the community, the research team will interview 6 to 10 community leaders with a deep understanding of these communities and/or of senior isolation and caregiving in Ottawa.

Ethics: The proposed project has been approved by the Carleton University Research Ethics Board-B (Clearance #106090), and will be conducted in ways that protect the privacy and confidentiality of all participants.

Eligibility Criteria for Key Informants:

- Provides or funds social programming and/or is involved in at least one ethnocultural community
- Can speak to the current situation for senior informal caregivers
- Must be able to provide written consent to participate in the study

The results of this study will be shared with participating communities, as well as potentially with other stakeholder groups, such as Age-Friendly Ottawa and PHAC, with the hope of assisting communities to secure future funding for further caregiver and senior programming.

15.4 Appendix D – Schedule for Focus Group Discussions and Interviews

	Date	Community	Type of Session	Number of participants
1	January 21, 2017	Chinese	Focus Group	4
2	January 31, 2017	Social Planning Council of Ottawa	Key Informant	1
3	January 31, 2017	Social Planning Council of Ottawa	Key Informant	1
4	February 1, 2017	Sri Lankan	Key Informant	1
5	February 2, 2017	Vietnamese	Key Informant	1
6	February 2, 2017	Vietnamese	Caregiver Interview	1
7	February 3, 2017	Indo-Canadian	Focus Group	6
8	February 6, 2017	Chinese	Focus Group	8
9	February 6, 2017	Sri Lankan	Caregiver Interview	1
10	February 7, 2017	Indo-Canadian	Caregiver Interview	1
11	February 8, 2017	Nepalese	Focus Group	9
12	February 8, 2017	Nepalese	Key Informant	1
13	February 8, 2017	Polish	Focus Group	3
Total number of participants:				38

15.5 Appendix E – Confidentiality Agreement for Translators



Confidentiality Agreement for Translators

CUREB-B Clearance #106090

During the course of your participation with the *Understanding Social Isolation and its Relationship with Care Provision for Older Adults in Ethnocultural Communities in Ottawa* research project, you may hear sensitive and/or personal information regarding our research participants being discussed. Information may include, but is not limited to, research participants' date of birth, place of employment, medical conditions, home address, or personal history. Such information should be treated in a confidential manner and should not be part of any public or private conversation. With respect to this information, and all other confidential information, the volunteer translator has read, understands, and agrees to the following:

1. I acknowledge the confidentiality of all research participant information and other confidential information. This information will not be revealed to, distributed to or discussed with anyone other than the research team.
2. I will not attempt to alter, change, modify, misinterpret, add, or withhold research participant stories or comments unless specifically instructed to do so by the research participant or a member of the research team.
3. Personal or identifying information about research participants (such as name, address, and/or telephone number) will not be released to unauthorized individuals or agencies.
4. I understand that information acquired during the course of my work/ volunteer assignment may not be utilized for personal gain or benefit.
5. I understand that misuse of personal information or data obtained through my involvement with this research project is a violation of these agreements and grounds for immediate disciplinary action.

Signed this _____ day of _____, 20__.

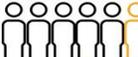
Name: _____ Signature: _____

15.6 Appendix F – Infographic

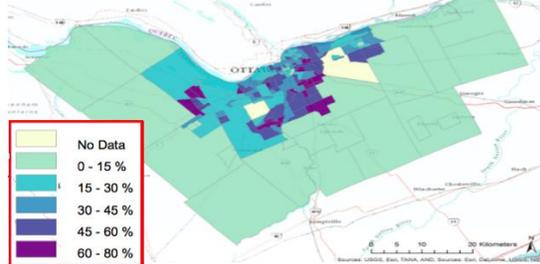
Triple Jeopardy: Caregiving Challenges, Language Barriers, & Precarious Support among Unpaid Ethnocultural Caregivers in Ottawa



Mehreen Anjum, Natalie Fersht, Hayley Miloff, Laura O'Dell, & Claire Pilon-Robertson
with the Social Planning Council of Ottawa
Supervisors: Dr. Susan Braedley & Dr. Renate Ysseldyk

-  1 in 2 Canadians will provide care for a family member or friend with a long-term health condition, disability or aging need.
-  As of 2015, 1 in every 6 Canadians was aged 65 years or older.
-  By 2036, 1 in 2 Canadians will be an immigrant or second-generation person with at least one parent born abroad.

Visible Minority Distribution in Ottawa



Ottawa ranks 6th highest in Canada for proportion of foreign-born individuals.



Triple Jeopardy

-  Community-based participatory research
-  Mixed-methods study
-  Ethnocultural caregivers in Ottawa face a triple jeopardy



Jeopardy 1: Caregiving is Challenging

-  Caregiving is challenging regardless of age or ethnicity.
-  Caregivers discussed difficulty in maintaining a healthy work-life balance.
-  As a result of a lack of support from the healthcare system, caregivers feel a need for respite support and caregiver training.

Jeopardy 2: Ethnocultural Caregivers Face Cultural Barriers

-  Ethnocultural caregivers provide substantial interpretation assistance for their care recipients, especially in their interactions with health professionals.
-  Ethnocultural caregivers face language and cultural barriers in accessing appropriate long-term care for their care recipients.

Jeopardy 3: Precarious Community Support

-  Ethnocultural community support in Ottawa is a key factor in mitigating caregivers' experience of social isolation.
-  Community programs are precarious when the following components are not in place:
 1. access to meeting spaces,
 2. availability of volunteer coordinators to organize activities,
 3. reliability of transportation to get to and from events.
-  Adequate funding is required to ensure these 3 components are sustainable.

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