Access to Health and Social Services for Racial and Ethnic Minority Family Caregivers of Older

Adults: Unmet Needs, Satisfaction with Health and Social Services, and Service Use

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Preface

This dissertation is submitted in partial fulfillment of the requirements of the degree of Doctoral of Philosophy in Social Work. This dissertation is an original, unpublished, independent work by the author, Eunyoung Lee.



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English Abstract

Background: Health and social services can help family caregivers of older adults with chronic conditions manage their caregiving demands. Yet the growing number of racially and ethnically diverse caregivers are less likely to use and experience benefits from such services than caregivers from non-minority groups. While individual and cultural factors, such as preferences for informal support, have most typically been used to explain this trend among racial and ethnic caregivers, previous research has overlooked environmental issues (e.g. discrimination and cultural incompatibility in health and social services) in terms of service access.

Aim: The overall aim of this doctoral dissertation is to quantitatively examine how population characteristics and environmental factors impact minority family caregivers' access to health and social services when supporting older adults. Specifically, this dissertation has three main interrelated research questions: (1) are specific population characteristics and cultural incompatibility associated with unmet needs among minority family caregivers?, (2) does cultural incompatibility in the health and social system affect minority family caregivers of older adults' overall satisfaction with health and social services?, and (3) does perceived daily discrimination impact health and social service use among minority family caregivers?

Methods: A cross-sectional survey design was used to collect data using a combination of validated and developed measures. Environmental factors, such as daily discrimination and cultural incompatibly, were measured using validated scales such as the Everyday Discrimination Scale and the Cultural Incompatibility subscale of the Service Barriers scale. Service access factors such as service use, unmet needs, and service satisfaction were measured using survey items developed for this dissertation. Racially and ethnically diverse family caregivers supporting an older person (age 65 or above) were invited to participate. Using purposive and snowball sampling



techniques, racially and ethnically diverse family caregivers, supporting an older person 65+ were recruited from a variety of health and social service agencies, community agencies, and religious organizations located in Montreal, Quebec. Recruitment was multifaceted and included on-site recruitment by the researcher, invitation by service providers and self-selection via newsletters and flyers. Bivariate and multivariate analyses were used to address the study questions. All data was managed using SPSS version 24.

Results: One hundred and two racial and ethnic minority family caregivers of older adults completed surveys. Key findings revealed that (1) protective factors for minority family caregivers' unmet service needs included strong connections to religious communities, cultural compatibility, and experience with using ethnic-specific services, (2) caregivers encounters with cultural incompatibility were significantly associated with decreases in their satisfaction with health and social services and heightened risk for unmet service needs, and (3) caregivers with histories of daily discrimination utilized services similarly to those who did not display such histories.

Conclusion: Minority family caregivers have experiences of cultural incompatibility in health and social services that can impact their satisfaction with services and hinder their capacities to have their needs met. It appears that daily discrimination may not significantly impact service use although further research is needed in this area. While strong connections with community groups and use of ethnic specific services can improve access for minority caregivers, it is incumbent upon service providers within the general health and social service networks to ensure services are responsive and sensitive to the needs of ethnically and racially diverse caregivers.



French abstract

Contexte: Les services de santé et les services sociaux peuvent aider les aidants naturels des personnes âgées atteintes de maladies chroniques à gérer leurs demandes de soins. Pourtant, le nombre croissant de soignants racialement et ethniquement divers est moins susceptible d'utiliser et de bénéficier de ces services que les soignants issus de groupes non minoritaires. Alors que les facteurs individuels et culturels, tels que les préférences pour un soutien informel, ont généralement été utilisés pour expliquer cette tendance chez les soignants raciaux et ethniques, les recherches antérieures ont négligé les facteurs environnementaux (par exemple, la discrimination et l'incompatibilité culturelle dans les services de santé et les services sociaux) en termes d'accès aux services.

Objectif: L'objectif général de cette thèse de doctorat est d'examiner quantitativement comment les caractéristiques de la population et les facteurs environnementaux influent sur l'accès aux services de santé et aux services sociaux des aidants familiaux minoritaires lorsqu'ils soutiennent les personnes âgées. Plus précisément, cette thèse comporte trois principales questions de recherche interdépendantes: (1) est-ce que des caractéristiques populationnelles et l'incompatibilité culturelle sont associées aux besoins non satisfaits parmi les aidants familiaux minoritaires, (2) l'incompatibilité culturelle dans le système de santé et social affecte-t-elle la satisfaction globale des aidants familiaux minoritaires soutenant des personnes âgées à l'égard des services de santé et sociaux? et (3) la discrimination quotidienne perçue a-t-elle un impact sur l'utilisation des services de santé et des services sociaux parmi les aidants familiaux minoritaires?

Méthodes: Un plan d'enquête transversal a été utilisé pour recueillir des données à l'aide d'une combinaison de mesures validées et développées. Les facteurs environnementaux, tels que la



discrimination quotidienne et l'incompétence culturelle, ont été mesurés à l'aide d'échelles validées telles que l'échelle de discrimination quotidienne et la sous-échelle d'incompatibilité culturelle de l'échelle des barrières de service. Les facteurs d'accès aux services tels que l'utilisation des services, les besoins non satisfaits et la satisfaction des services ont été mesurés à l'aide des éléments d'enquête développés pour cette thèse. Des proches aidants de diverses origines raciales et ethniques soutenant une personne âgée (65 ans ou plus) ont été invités à participer. À l'aide de techniques d'échantillonnage ciblé et de boule de neige, des aidants naturels de diverses origines raciales et ethniques, soutenant une personne âgée de 65 ans et plus, ont été recrutés dans divers organismes de santé et de services sociaux, organismes communautaires et organisations religieuses situés à Montréal, au Québec. Le recrutement était multiforme et comprenait le recrutement sur place par le chercheur, l'invitation par des fournisseurs de services et l'auto-sélection via des bulletins d'infromation et des dépliants. Des analyses bivariées et multivariées ont été utilisées pour répondre aux questions de l'étude. Toutes les données ont été gérées à l'aide de SPSS version 24.

Résultats: Cent deux soignants familiaux des minorités ethniques et raciales soutenant des personnes âgées ont répondu aux sondages. Les principales constatations ont révélé que (1) les facteurs de protection des besoins non satisfaits des aidants familiaux minoritaires comprenaient des liens solides avec les communautés religieuses, la compatibilité culturelle et l'utilisation de services ethniques, (2) des expériences d'incompatibilité culturelle par les aidants naturels étaient significativement associées à une diminution des leur satisfaction à l'égard des services de santé et des services sociaux et le risque accru de besoins de services non satisfaits, et (3) les soignants ayant des antécédents de discrimination quotidienne ont utilisé les services de la même manière que ceux qui n'ont pas affiché de tels antécédents.



Conclusion: Les aidants familiaux minoritaires ont des expériences d'incompatibilité culturelle dans les services de santé et sociaux qui peuvent influer sur leur satisfaction à l'égard des services et entraver leur capacité à répondre à leurs besoins. Il semble que la discrimination quotidienne n'ait pas d'impact significatif sur l'utilisation des services, bien que des recherches supplémentaires soient nécessaires dans ce domaine. Bien que des liens étroits avec les groupes communautaires et l'utilisation de services ethniques puissent améliorer l'accès aux service pour les aidants naturels issus de minorités, il incombe aux fournisseurs de services au sein des réseaux généraux de santé et de services sociaux de veiller à ce que les services soient sensibles et prêts à répondre aux besoins des soignants ethniquement et racialement divers.



Chapter 1. Introduction

Statement of the Problem

The growth of older adults 65+ in the Canadian population over the past 20 years (from seven percent to 14 % of the population; Statistics Canada, 2016) is expected to continue and to cause influential changes in the economy, society, and health care system over the next two to three decades (Canadian Medical Association, 2013). Older adults, regardless of their health conditions, prefer to live at home rather than in an institution (Sabia, 2008; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). This places great demands on family members who provide approximately 80% of the caregiving duties in the community (Carstairs & Keon, 2009). In fact were it not for family caregivers who enable older adults with chronic illnesses to remain in the community, the demands on Canada's health care system would increase substantially (Ploeg et al., 2017). While no statistical information is available that specifically identifies the prevalence of racial and ethnic minority family caregivers caring for older adults in Canada, it is known that more than 21% of Canadians serve as caregivers for family members or friends (Sinha, 2013). In addition, family caregivers of the visible minority population (e.g. Black and South Asian) tend to provide more caregiving and are disadvantaged in accessing services compared to non-minority family caregivers (Greenwood, Habibi, Smith, & Manthorpe, 2015; Rote & Moon, 2018).

To help family caregivers and their care recipients, policy makers and service agencies have provided medical and social services such as respite care and day programs (Li, Kyrouac, McManus, Cranston, & Hughes, 2012; Sussman & Regehr, 2009). Despite the availability of services, several studies have indicated that people from minority racial and ethnic backgrounds in North America tend to underutilize health and social services compared to their non-minority group counterparts, and when racial and ethnic minority group members do utilize services, they



typically do not receive a sufficient amount of support from service providers (Giuntoli & Cattan, 2012; Stewart et al., 2011). Hence, racial and ethnic minority caregivers may be experiencing difficulties in accessing the available services, which may lead to unmet service needs that could exacerbate the challenges they face in providing support to family and friends in the community (Shommu et al., 2016).

Accessibility of health and social services is an important principle in Canada. In fact, it is one of the five principles of the Canada Health Act (CHA) which requires that, "the provincial and territorial plans must provide all insured persons reasonable access to medically necessary hospital and physician services without financial or other barriers" (Health Canada, 2015). While services such as community and home support have not been covered under that act, the principle of universal access is nevertheless an important one in Canadian society. Within this context, it can be presumed that Canadians value the right to service access for all residents regardless of their racial/ethnic background. However, racially and ethnically diverse caregivers ¹(also referred to as minority family caregivers) face barriers in their daily lives and in interactions with service providers which limit their access to services due to the combined disadvantages related to environmental factors such as cultural incompatibility in health and social services, and discrimination (Lai & Surood, 2013; Garcés, Scarinci, & Harrison, 2006; Greenwood et al., 2015).

While these environmental factors likely affect indicators of service access such as service use, satisfaction with services, and unmet service needs, previous studies have rarely focused on how environmental factors faced by minority family caregivers of older adults impact

¹ Although the researcher in the study is aware that there are other types of minority groups than those marginalized by their race and ethnicity and that there are other types of caregivers than family caregivers, for the purpose of this dissertation study, racially and ethnically diverse minority family caregivers will be referred to as minority family caregivers.



their experiences of service access when supporting older adults in the community (see the following for exceptions: Browne et al., 2014; Burgess, Ding, Hargreaves, Van Ryn, & Phelan, 2008; King, Lindsay, Klassen, Esses, & Mesterman, 2011). Instead, previous research has predominately focused on population characteristics (e.g. socioeconomic status, racial groups) and preferences to explain underuse of services or dissatisfaction with services – for example, attributing non/underuse to familial obligation or a preference for community reliance (Giuntoli & Cattan, 2012; Stewart et al., 2011).

Redressing these gaps in the literature and building on the limited research in this area of scholarship, this dissertation aims to examine associations between environmental factors (including cultural incompatibility and daily discrimination) and indicators of service access. In this dissertation, cultural incompatibility is defined as service agencies' lack of cultural/religious sensitivity, limited language capacity, and lack of specialized programs for racial and ethnic minority clients. This definition of cultural incompatibility was developed based upon how the concept of cultural incompatibility was used in other studies in the literature (Lai & Surood, 2013; Scharlach et al., 2006). Previous literature highlights that culturally, linguistically, and religiously inappropriate services can make minority family caregivers feel socially isolated and experience a higher level of care burden when accessing health and social care services (Ahmed et al., 2016; Dias, Gama, & Rocha, 2010). Given that the high prevalence of cultural incompatibility effects clients' access to health and social services, it is necessary to examine how cultural incompatibility in health and social services impacts satisfaction with health and social services among minority family caregivers.

Daily discrimination is another environmental factor studied in this dissertation.

Discrimination is generally defined as a situation in which a person treats a person of another



racial or ethnic group differently from members of their own group with the intent to differentiate or harm them (Utsey, Ponterotto, Reynolds, & Cancelli, 2000). More specifically, daily discrimination refers to discrimination targeting an individual and which occurs in everyday life. Given that previous literature suggests that people with racial and ethnic minority status generally underuse health and social services and that literature indicate that discrimination can impact health service use among people with racial and ethnic minority status (Dilworth-Anderson, Williams, & Gibson, 2002), the current study examines how daily discrimination may particularly affect health and social service use by minority family caregivers.

Specific Aims of the Three-Paper Dissertation

The overall aim of this dissertation is to explore the extent to which population characteristics and environmental factors impact minority family caregivers' access to health and social service when supporting their older relatives. In this dissertation, service access is represented by three different outcomes explored in three distinct but related papers: unmet service needs, satisfaction with services, and health and social services use.

The first paper examines the impact of population characteristics (e.g. age, gender, employment status, and transportation) and an environmental factor (i.e. cultural incompatibility) on unmet health and social service needs among minority family caregivers. In this paper, unmet service need is measured by the extent to which services identified as needed by minority caregivers are actually used by them. This mismatch between need and service use is an important indicator of service access.

The second paper explores the association between the environmental factor 'cultural incompatibility' and the access indicator 'service satisfaction.' To express satisfaction with health



and social services, family caregivers report their experiences with services used to date. Unlike the measure of unmet need used in study one, this paper considers the caregivers' experiences with services they have already managed to access.

The last paper of this dissertation examines how the environmental factor 'daily discrimination' affects health and social service use among minority family caregivers. Health and social service use represents another indicator of whether minority family caregivers have accessed particular services. Daily discrimination is an environmental factor that has been identified as a prevalent experience for minority adults but has not as yet been explored in relation to service use for minority family caregivers. Hence this third paper adds an important new dimension to the relationship between environmental factors and service access for minority caregivers.

Literature Review

The literature review is comprised of three sections. The first section reviews the literature on access to health and social services. The second section of the literature review is an introduction to the theoretical model used across the three papers in this dissertation, the Andersen Behavioral Model of Health Care Use (Andersen, 1995), as well as a literature review of studies which use this model. The final section presents the modifications of the Andersen Model tailored to the current study on access to health and social services by family caregivers from racial and ethnic minority groups.

Section 1: Literature Review on Access to Health and Social Services

This section is broken up into literature related to each of the three indicators of access to health and social services (i.e. unmet needs, satisfaction with services, and service use), as well as the literature related to the two environmental factors (i.e. cultural incompatibility and daily



discrimination). The subsections include literature related to: a) minority caregivers and unmet needs, b) minority caregivers and satisfaction with services, c) minority caregivers and service use, d) cultural incompatibility and service access, and e) daily discrimination and service access. Gaps in the existing literature are highlighted in each subsection, with the primary gap in each of the service access subsections being a lack of literature on the impact of environmental factors on service access. These gaps in the literature are more fully explored in a separate subsection.

Minority Caregivers and Unmet Needs

Making sure that minority family caregivers' needs for health and social support are being met (i.e. met needs) is important to the caregiving process. Needs that are not sufficiently addressed (i.e. unmet needs) may have a negative impact on caregivers and their loved ones with chronic illnesses. The current body of research literature has examined general predictors of unmet needs among family caregivers and immigrants (Beach & Schulze, 2017; Li, Kyrouac, McManus, Cranston, & Hughes, 2012). It should be noted that there is limited literature regarding predictors of unmet needs for minority caregivers. Some studies, however, have examined the relationship between population characteristics (e.g. socio-demographic factors) and unmet needs among minority caregivers. For example, Li (2004) examined service barriers and unmet needs among Asian American caregivers, and found that a higher level of unmet needs was associated with: care recipient's chronic conditions, lack of informal support, and caregivers' level of educational attainment. Black, Johnston, Rabins, Morrison, Lyketsos, and Samus (2013) revealed that caregivers who were nonwhite, experienced a higher level of depression, and possessed less education were affiliated with a higher level of unmet needs. Corroborating the results from previous studies, Casado, van Vulpen, and Davis (2011) explored unmet needs in six types of community-based services and found that black caregivers, care recipients with a higher level of Activities of Daily Living and Instrumental Activities of Daily



Living, care recipients with a higher level of behavioral issues, and a lack of support from others were associated with unmet needs. Findings from this literature indicate that minority caregivers report higher levels of unmet needs when compared to white caregivers. Findings further reveal that age, mental health issues, and educational status of caregivers, functional challenges of care recipients, and limited support may play a role in the levels of unmet needs reported by minority caregivers. Although it is apparent from these findings that population characteristics are important when examining unmet needs, none of the literature above accounts for the environmental factors specific to minority caregivers (such as cultural incompatibility) that may be impacting their unmet needs.

Minority family caregivers in North America report more negative experiences (e.g. discrimination, satisfaction with services, etc) while using health and social service agencies in comparison to family caregivers from the dominant group (Benjamins, 2012; Burgess et al., 2008; Greenwood et al., 2015). These negative experiences may contribute to unmet service needs for minority family caregivers. In spite of the importance of this topic, the literature about unmet service needs is limited. Therefore, examining the predictors of unmet service needs is crucial to a better understanding of the use of health and social services among minority family caregivers of older adults. Additionally, while population characteristics may give some indication of how particular groups experience differential access to services (i.e. unmet needs) they do not identify the outside influences which may also be impacting this access. Therefore, this dissertation also aims to examine if environmental factors (e.g. cultural compatibility) play a role in this differential access to services (i.e. unmet needs).

Minority Caregivers and Satisfaction with Services

Determining client satisfaction is a common way to evaluate the quality of health and social care services- a more pressing task with the growing need for social and health care



services (Jenkinson et al, 2002). Health care studies have shown that racial and ethnic disparities in terms of quality of services received still exist (LaVeist, & Nuru-Jeter, 2002; Sambamoorthi & McAlpine, 2003; Shelley, Russell, Parikh, & Fahs, 2011). More specifically, a limited number of studies have been conducted which examine satisfaction with services among minority caregivers (Eaves, 2002; Epstein et al., 2015; Ngui & Flores, 2006; Wallace Williams, Desai, Rurka, & Mutran, 2008). Eaves (2002) examined satisfaction with health care among rural African Americans and found that the caregiver participants were dissatisfied with health care services. Three studies have been conducted comparing satisfaction with services among caregivers of differing racial groups; however, each reported differing results. For example, the Ngui and Flores (2006) study, which investigated the relationship between racial/ethnic disparities and satisfaction with care in healthcare services among family caregivers who have patients with special needs, found that Black and Hispanic caregivers were more dissatisfied with services in healthcare settings than white caregivers. In contrast, two other studies on satisfaction (Epstein et al., 2015; Wallace et al., 2008) have shown that there were no significant differences in the level of overall satisfaction among racial caregiver groups (e.g. White vs African American or White vs Latino).

Although this literature indicates that racial and ethnic minority family caregivers may have negative experiences while utilizing health and social services, evidence about the satisfaction with services for minority caregivers is mixed in the caregiving and service satisfaction literature (Greenwood et al., 2015). In addition, the research literature in this area is primarily concentrated on the United States. As the service systems in the United States are vastly different from those in Canada, and as the experiences of the caregivers are likely to impact their willingness to access the health and social service system, filling these gaps in the



literature can provide insight to the problem of how to improve racial and ethnic minority family caregivers' access to health and social services in Canada.

Minority Caregivers and Service Use

While the number of older adults from minority groups is rising in Canada (Statistics Canada, 2016), minority caregivers tend to be underrepresented in service use literature. Some comparison studies have indicated that minority caregivers tend to use community agency-based services less when compared to their dominant racial group counterparts (e.g. White caregivers; Dilworth-Anderson et al., 2002; Greenwood et al., 2015; Mausbach et al., 2004; Scharlach et al., 2006). In addition, studies report that when minority caregivers use services, they typically do not receive sufficient support from service providers (Giuntoli & Cattan, 2012; Stewart et al., 2011). Some studies which have investigated why minority caregivers use less services report that these caregivers: prefer to ask help from their family members, lack language proficiency (Greenwood et al., 2015; Han et al., 2008), are unfamiliar with the health system (Herrera, Lee, Palos, & Torres-Vigil, 2008), and experience cultural differences (Chow et al., 2010; Giuntoli & Cattan, 2012). Other studies suggest that the less frequent use of services is due to a cultural preference for informal support (e.g. family and friends) and a preference for community-based services (Kong et al., 2010; Pinquart and Sörensen, 2005; Sun, Lee Rooff, Klemmack, & Burgio, 2008; Woodward, 2011).

This foray into the literature regarding the lack of service use among minority caregivers has primarily focused on either personal characteristics or cultural preferences. Hence, examination of the environmental factors that might impact minority caregivers' use of services have remained relatively unexplored. More specifically, the potential impact of daily discrimination (i.e. an environmental factor) on service use has not been explored directly in the service use literature for minority caregivers.



Cultural Incompatibility and Service Access

A service agency can be referred to as culturally incompatible when it possesses a dearth of service provision in other languages, a shortage of cultural/religious awareness, and a limited number of programs specifically tailored for racial and ethnic minority caregivers (Lai & Surood, 2008; Greenwood et al., 2015). Some studies have indicated that the negative service experiences some minority caregivers have in health and social care settings may be related to cultural issues, including being unfamiliar with the social system, having language barriers, and cultural differences (Han et al., 2008; Lai & Surood, 2008; Stewart et al., 2011). For example, Scharlach and colleagues (2006) conducted qualitative research which examines the relationship between caregivers' service use and cultural attitudes among minority family caregivers. In their study, the authors found that minority family caregivers experienced difficulty in receiving culturally appropriate services from community based-service agencies even when those services were needed for their caregiving. Minority family caregivers felt that the service agencies did not consider the minority clients' specific needs. Stewart and colleagues (2006) conducted a study on immigrant women family caregivers in Canada and found that both caregivers and service providers expressed that current resources or programs in service settings did not provide enough support to minority family caregivers in terms of the client's culture and language. Furthermore, Regan, Bhattacharyya, Kevern, and Rana (2013) reported that religion might affect service access in the area of service use among minority caregivers in that service access may also be curtailed by the fear that their culture's religions may not be respected. Corroborating the results from previous studies, Lai and Surood (2008) explored service barriers among Chinese family caregivers using the concept of cultural incompatibility. In their study, they found that caregivers with lower income, financial inadequacy (i.e. participants' financial status did not satisfy their



needs), lack of English proficiency and shorter length of residence in Canada were associated with cultural incompatibility.

The notion that cultural incompatibility affects clients' access to health and social services is increasingly being recognized (Greenwood et al., 2015; Spencer et al., 2010). When service agencies do not respect cultural differences and fail to sustain the diversity of each minority group, cultural incompatibility is evident. This environmental factor (i.e. cultural incompatibility) may impact clients' satisfaction with services which could in turn lead to an underuse of the available services for family caregivers (i.e. unmet needs). Unfortunately, there is a dearth of studies which examine the relationship between cultural incompatibility in health and social services and either unmet service needs or satisfaction with services among racial and ethnic minority family caregivers in a Canadian setting.

Daily Discrimination and Service Access

Regarding service access and discrimination, the majority of studies have focused on the relationship between discrimination and service use rather than the other indicators of service access (unmet needs or satisfaction with services). Due to this lack of literature on other indicators of service access among minority caregivers, this section specifically considers the relationship between discrimination and service use. Previous research on service use has found that minority family caregivers underuse agency-based services (Beach & Schulz. 2017; Li et al., 2012; King et al., 2011), however discrimination was not examined as a possible cause in those studies. Although population characteristics have typically been used when predicting patterns of service use (e.g. a preference for familial care is often cited; Chun, Knight, & Youn, 2007; Losada et al., 2010), evidence is increasingly pointing to discrimination as an aspect of a caregiver's environment which may impact a client's use of services. For example, discrimination may occur both within and beyond health and social service settings (Spencer et



al., 2010; Van Ryn et al., 2011), and there is evidence that discrimination experienced outside of service settings can have a significant impact on service use (Ben, Cormack, Harris, & Paradies, 2017; Burgess et al., 2008; Burrow & Ong, 2010).

As a consequence, a growing number of scholars are calling for more attention to the impact of discrimination on service use with racially and ethnically diverse groups (Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007; Huang, Appel, & Ai, 2011; Shavers et al., 2012; Spencer et al., 2010). The type of discrimination investigated in the majority of these studies is referred to as daily discrimination in this paper (i.e. discrimination encountered in everyday life). A few studies to date have examined discrimination and services for family caregivers in general (though not for minority family caregivers of older adult relatives); and other studies have looked at how people from racially and ethnically different groups experience discrimination and health services (though not specifically family caregivers). As a result of the lack of literature on minority family caregivers, this literature review will cover studies from each of these parallel populations instead.

A few recent studies, which used the National Latino and Asian American Study data have examined discrimination and health service experiences. Spencer and colleagues (2010) investigated the relationship between perceived discrimination (e.g. day-to-day mistreatment experiences because of race/ethnicity) and mental health service use among the Asian American population. They found that perceived discrimination was not associated with clients' use of mental health services. The finding suggests that discrimination among minority group members may not impact use of mental health services. However, these findings differ compared to other research, which indicates that a higher level of experience with discrimination is associated with less use of agency-based services (Burgess et al., 2008; Chae, Lee, Lincoln, & Ihara, 2012). Due



to this conflict, clarification is needed when examining the relationship between daily discrimination and health and social service use. The answer to this conflict, however, may be addressed in the next group of studies examined.

The relationship between discrimination and service use may differ based on the types of discrimination examined, and the specific minority groups to which a client belongs. In one study, Benjamins (2012) explored how discrimination affects preventive service utilization (e.g. types of cancer screening service) among various racial and ethnic groups. The authors examined three areas related to discrimination (though each are aspects of daily discrimination as defined in this paper): the experience of discrimination (e.g. frequency of discrimination due to race/ethnicity in specific situations such as at school, or while getting service in a store or restaurant), everyday discrimination (e.g. day-to-day mistreatment experiences), and discrimination in health care (e.g. being treated "better, worse, or the same compared with people of other races/ethnicities" when accessing health care; Benjamins, 2012, p. 871). The use of preventative services varied among the racial and ethnic groups depending on the particular aspect of discrimination examined. For example, everyday discrimination was associated with the use of only one out of the six examined preventative services. Additionally, this result was only valid for two out of the four racial/ethnic groups (both minority groups) included in the study. These results indicate that the differences in findings in the literature may be attributed to the aspect of discrimination examined as well as the race/ethnicity of the participants. If the impact of discrimination on service use varies based upon the participant's race or ethnicity, researchers may be getting different results based upon the specific minority groups included in the analyses. Additionally, some studies group all minority group members together and just compare between minority and nonminority groups in their analyses. However, as different



minority groups may experience different levels of daily discrimination, and/or may react differently to any discrimination that they receive, combining different minority groups in the same analyses may not reflect the nuances of how daily discrimination impacts each minority group as a separate entity.

The findings also indicate that the differences in the definition of discrimination may impact results. In this literature, many studies are defining discrimination differently and some are only using specific aspects of discrimination in their analyses — for example, measuring discrimination only in specific locations (e.g. at work), "major" acts of discrimination vs. "minor" acts of discrimination (e.g. not hiring someone because of race/ethnicity vs. making derogatory comments), or general/daily discrimination (i.e. a combination of the previously stated aspects of discrimination that occur throughout everyday life). It may be that the differences in the literature on discrimination and service use are due to the differing definitions for discrimination that the various researchers are using. For this reason, the current dissertation uses a more general definition of discrimination (i.e. daily discrimination) which encompasses many of the definitions of discrimination utilized in the current literature.

These suppositions are supported by an additional study by Burgess and colleagues (2008) which examined the relationship between discrimination and health care use by various racial and ethnic groups (e.g. White, U.S-born Black, African-born Black, American Indian, Hispanic, and Southeast Asian adults). They specifically focused on three types of discrimination: daily discrimination, discrimination in health care, and major discrimination. They also found that depending on the racial and ethnic grouping, there were differences between the types of discrimination participants experienced and their health care use. For example, in the total sample, all of the types of discrimination examined were associated with the utilization of mental health



care among various racial and ethnic groups except for discrimination in health care settings. This provides additional evidence that differences between the specific minority groups to which participants belong may also serve as an explanation for mixed findings between studies on discrimination and service use.

To contribute to the research literature, this dissertation study examines the relationship between discrimination and utilization of health and social services in Canada. This dissertation study also targets a more specific population (i.e. minority family caregivers of older adults) as previous studies have largely focused on strictly health settings (e.g. mental health, cancer care, etc.), as well as a specific type of discrimination (i.e. daily discrimination).

Gaps in the Existing Literature

A review on the existing literature regarding the impact of environmental factors (i.e. cultural incompatibility and discrimination) on service access for minority family caregivers has identified some important trends and directions for future research.

First, issues of service access have been noted in the literature by comparison studies identifying lower levels of service use and satisfaction, and higher levels of unmet needs amongst people with minority backgrounds. To date, there are some trends in comparison studies of service access issues among minority family caregivers; however, very few studies have examined the impact of these issues among minority family caregivers of older adults in Canada. Therefore, there is a lack of understanding about how minority family caregivers access health and social services (e.g. unmet needs, services use, and satisfaction with services) for themselves and their care recipients as a part of the caregiving process.

Second, although evidence is beginning to emerge noting the prevalence of cultural incompatibility experienced by minority family caregivers using health and social services, this environmental factor has not been examined in relation to minority caregivers' unmet service



need or satisfaction with services. By exploring the potential impact of cultural incompatibility in health and social services on unmet needs and service satisfaction, this dissertation will identify potential issues related to access to health and social services for minority family caregivers who are growing amongst the population of Canadian caregivers.

Finally, while discrimination in daily life has been documented amongst minority people living in Canada and there is some evidence that general experiences with discrimination may impact health service use, the extent to which daily discrimination impacts the use of health and social services by minority family caregivers has remained relatively unexplored.

Section 2: Theoretical Framework of This Dissertation Study: Andersen's Behavioral Model of Health Services Use

The widely used and influential Andersen Behavioral Model of Health Service Use (1995) was critical in informing the conceptual framework for all three papers of this dissertation (see Figure 1). This model was particularly useful for the proposed aims of this dissertation because it accounts for population characteristics and environmental factors that may impact service access, identifies some health behaviors (e.g. service use, unmet needs) and an outcome (e.g. service satisfaction) that together represent the components of services access and it has been used with a variety of minority groups (Casado et al., 2011; Hong, 2019). In it's original form Andersen's model (1995) included four components: environment factors, population characteristics, health behavior, and outcome. Using the broader concept of service access as an outcome (which includes use, unmet needs, and satisfaction), this dissertation used the components of Andersen's model to build a framework for uncovering factors that may impact access to health and social services for minority family caregivers of older adults with chronic illnesses. The next section will discuss each component of the model in detail, including a description and a review of the: environment, population characteristics, health behaviors, and outcomes.



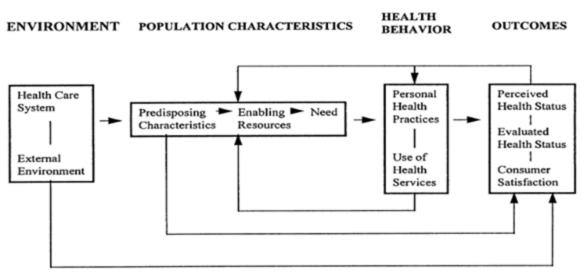


Figure 1: Andersen Behavioral Model of Health Service Use

An Emerging Model-Phases 4. Source: Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter?. *Journal of health and social behavior*, 36(1), 1-10.

Environmental Characteristics

According to Andersen's original model (1995), environmental characteristics that influence health service use include both characteristics of the health care system and the external environment. The health care system is defined as is defined as "policies, resources, organization, and financial arrangements influencing the accessibility, availability, and acceptability of medical care services" (Phillips, Morrison, Andersen, & Aday, 1998 p. 574); whereas the external environment can be considered as other factors outside of the health care system which may impact service access (e.g. the economic climate, politics, prevailing norms of society, etc; Phillips et al.,1998). Based on the review of the literature in previous sections, cultural incompatibility can be considered a key health service characteristic thought to impact service satisfaction and unmet needs. Situation such as insufficient attempts to sensitize staff and organizations to issues (considered important for racialized and non-Canadian born caregivers



(e.g. sensitivity to cultural religious beliefs, specialized programming, and availability of diverse languages) may have an important impact on service access for minority caregivers (Woodward, 2011). As noted previously, this health service characteristic is rarely accounted for in the literature exploring minority caregivers' perceptions of unmet needs and satisfaction with services. For this reason, it was considered a component of the health service system worthy of exploration. Further, daily discrimination, defined as negative experiences which minority family caregivers encounter in their daily lives as a consequence of their race/ethnicity and/or immigration status (Canadian Human Rights Commission, n.d; Ontario Human Rights Commission, 2008), represents a critical environmental condition that may play a pivotal role in minority caregivers' experiences with service access (most notable in their decisions to use/not use available services). Yet this component of the external environment has not as yet been included in models of service access for minority caregivers supporting older adults in the community. One again this points to a critical gap in the literature.

Population Characteristics

Population characteristics in the model contain three main components: 1) predisposing factors: population socio-demographic profile (for example gender, age, family size), which may differentially position particular groups of people to have more or less access to services; 2) enabling factors (for example income, social support, transportation) which are individual or structural resources that might help people access available services (Andersen, 1995); and 3) need factors (for example care recipient's physical functions, caregiving demands) which might drive an individual to consider accessing services. Recent iterations of the model have also explored how these factors come together to predict met/unmet needs for those individuals who are using health and social services (Casado, van Vulpen, & Davis, 2011; Marshall, 2011; von Heymann-Horan et al., 2013).



One of the limitations of the model as it has been applied in health and social service research has been the failure to consider the enabling and environmental factors that may be specific to minority family caregivers. For example, current research on service barriers and use has suggested that experiences with ethnic-specific services might affect service use and unmet service needs among people from marginalized groups (Sadavoy, Meier, & Ong, 2004; Spencer et al., 2010; Stewart et al., 2011), yet such factors to date have not been included in studies informed by this model. For the purposes of this dissertation, the enabling and environmental factors considered to be specific to racialized and ethnically diverse groups have been added to further capture the extent to which population characteristics may impact met/unmet service needs. Using this adapted version of the model to explore the extent to which predisposing, need, enabling and environmental factors are associated with service access (e.g. met/unmet needs) is an important aspect of this dissertation.

Health Behaviors

Health behaviors are actions which might influence an individual's health positively or negatively (Short & Mollborn, 2015). Accessing health and social services can be considered a health behavior as use of services can positively impact a caregiver's health or the health of their care recipient. Many previous studies have included service use or unmet service needs as health behaviors in the model (Beach & Schulze, 2017; Lam et al., 2011). Service use and unmet needs are two sides of the same coin. Service use is an indication of services which have been used by participants, while unmet needs indicates services which have not yet been used by participants (but which participants need). Both of these components reflect the behaviors of the participants through their choice either to use, or not to use, particular services.

As the 1995 version of the Andersen model illustrates, health behaviors (e.g. personal health practice and use of health services) can be used as either an outcome or an independent



variable. For example, Casado, van Vulpen, and Davis (2011) examine individual characteristics and unmet needs. In their study, unmet needs was analyzed as an outcome variable. Another example is that Fortin, Bamvita, and Fleury (2018) examine patient satisfaction with mental health services. In their study, the service use was considered to be an independent variable. In both instances, even though their position in the data analysis were different, both of these variables were considered to be health behaviors. As such, indicators of service access like caregivers' use of health and/or social services and unmet service needs can be considered as health behaviors in the Andersen model.

Outcome

As the 1995 version of the Andersen model illustrates, client satisfaction with services or health status have used as outcomes of health and social service access. It should be noted that the 'outcome' listed in the Andersen model does not refer to the outcome variables in the data analyses. Instead, Andersen is referring to the ultimate goal which he states is the reason for promoting service use: client satisfaction (Andersen, 1995). He points out that although increasing service use is the goal of many interventions and policies and is the focus of the model, service use is not the ultimate outcome. The point of having services in the first place is to improve client's lives. Relatively few studies have focused on the outcome portion of the Andersen Model, however, of the few who have, several have used service satisfaction as an outcome variable (Fortin, Bamvita, & Fleury, 2018; Ivanov, 2000; Kilbourne et al., 2006; Lippens & Mackenzie, 2011). Apart from being the ultimate goal in the model, consumer satisfaction is also a barometer of the quality of services. Going along with the literature, the current dissertation will therefore utilize minority family caregiver's satisfaction with health and social services as an outcome.

Proposed Framework to Investigate Access to Health and Social Services

For this dissertation, the proposed conceptual framework was adapted from the Andersen



Behavioral Model (Andersen, 1995) shown in Figure 2. This figure shows how population characteristics and environment factors may affect access health and social services (e.g. service use, unmet needs, and satisfaction with services) among minority family caregivers of older adults.

First, all three of the papers in this dissertation examine the effects of environmental factors on service outcomes and health behaviors. Even though environmental factors (e.g. discrimination and cultural incompatibility) may explain disparities in service access among minority family caregivers, the majority of the previous studies have only examined population (individual) characteristics and health behaviors. Therefore, in this dissertation, it is necessary to examine how discrimination or cultural incompatibility (as environmental factors) affect access to health and social services. Therefore, using an adapted version of the model, the three papers in this dissertation examine the relationships between cultural incompatibility, population characteristics and unmet needs (study 1), the relationship between cultural incompatibility and satisfaction with health and social services (study 2), and the relationship between daily discrimination and service use (study 3) among minority family caregivers.

Second, this version of the model utilizes a cultural variable (i.e. ethnic-specific service use) as an enabling factor in the population characteristics category. Enabling factors are resources which protect or impede unmet service needs. As the use of ethnic specific services permit minority caregivers to more easily utilize services, this variable is considered an enabling factor in this study. Although many studies that have used the Anderson model (1995) have measured the relationship between population characteristics (e.g. predisposing, need, and enabling) and health behaviors (e.g. service use or unmet service needs) among diverse populations, previous studies which targeted older adults and minority group members have typically utilized a similar selection of predisposing, needs, and enabling variables in their



models. The existing literature has not included the use of a cultural resource (e.g. ethnic-specific service use) as an enabling factor in the model. Enabling factors are resources which protect or impede unmet service needs. Therefore, the first paper of this dissertation (which examines the relationships between an environmental factor, population characteristics and unmet needs) includes a cultural resource variable (i.e. ethnic-specific service use) in the model. Utilizing this cultural resource as one of the population characteristics may help uncover the impact of unmet service needs among minority family caregivers.

Access to Health and Social Services Environment Health Behavior Outcome External environment Service use Discrimination **Population Characteristics Satisfaction** with services Health care system **Unmet needs** Cultural **Predisposing** incompatibility Need **Enabling**

Figure 2. Proposed Framework to Investigate Access to Health and Social Services

Summary, Data Collection, and Chapter Overview for Three Articles of This Dissertation

Investigating access to the Canadian health and social services system for minority family caregivers of older adult relatives is the primary focus of the three articles of this dissertation. By exploring the potential impact of population characteristics and environmental factors on minority family caregivers' unmet service needs, satisfaction with health and social services, and service use, this dissertation study hopes to identify potential issues related to service access for this growing population of Canadian caregivers and, thus, prevent further marginalization. This dissertation will also raise awareness of the hidden effects of discrimination and cultural incompatibility on access to health and social services by minority family caregivers.

This dissertation includes three components that are presented as three distinct papers. The first paper examines the predictors (e.g. population characteristics and an environmental factor) of unmet needs for health and social services among racial and ethnic minority family caregivers of older adult relatives with chronic illnesses in Canada. The second paper explores the associations between cultural incompatibility in the health and social service context and satisfaction with health and social services among minority family caregivers. The third paper examines how daily discrimination affects health and social service use among minority family caregivers.

Inclusion Criteria for this Dissertation

This three-paper-based dissertation utilized data collected during a survey conducted with 102 racial and ethnic minority family members of community-residing older adult relatives (65+) with degenerative physical and cognitive chronic conditions that require ongoing support. The inclusion criteria for participation in the dissertation study were that 1) participants were 21 years or older, 2) participants had enough language capacity to complete the questionnaires in English or French with some assistance, 3) participants were either immigrants to Canada from



non-French or English speaking countries or members of ethnic or racial minority groups, 4) participants were primary unpaid caregivers of persons 65+, residing in the community and requiring assistance with at least two ADLs/IADLs, 5) participants had used or tried to use health and social services to support their caregiving within the last 12 months, and 6) participants lived in Montreal.

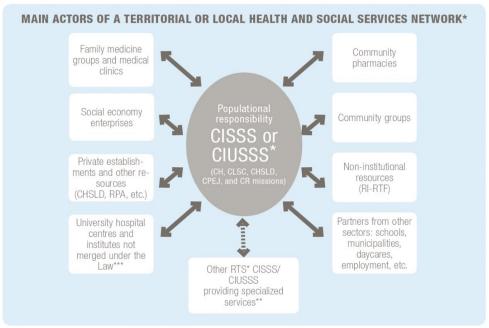
Using purposive and snowball sampling techniques, the researcher recruited potential participants at several health and social service agencies and community and religious organizations located in Montreal, Quebec.

Context of Health and Social Services in Quebec

The Quebec health and social services system consists of the Ministère de la Santé et des Services sociaux (MSSS), its agencies, and the system institutions. The MSSS and integrated health and social services centres share the functions and responsibilities of providing health and social services to the population of Quebec. The province is divided into 18 regions, each with an integrated health and social services center (e.g. CISSS or CIUSSS, depending on whether the centre has a university teaching and research mandate) which provide health and social services on the local scale through its affiliated agencies. As shown in Figure 3, the integrated centers usually provide guidelines to where people can access health and social services in their territorial service network-such as medical clinics and family medicine groups, and community groups (Ministère de la Santé et des Services sociaux., n.d).



Figure 3. Main Actors of a Territorial or Local Health and Social Services Network (Source: "Health and Social Services System in Brief" by Ministère de la Santé et des Services sociaux).



- * Any given RTS may include more than one RLS that uses identical categories and partners at the local level.
- ** The CISSS or CIUSSS must establish, if necessary, regional or interregional service corridors in order to complete the services provided to the population of their territory.

 *** An Act to Modify the Organization and Governance of the Health and Social Services Network, in Particular by Abolishing the Regional Agencies (CQLR, c. 0-7.2).

Five CIUSSSs exist on the island of Montreal with the mandate to: 1) assist clients in accessing health and social services promptly, 2) provide good quality of service, 3) provide advice how to improve healthy life style, and 4) assist in the betterment of the health of the district population in conjunction with their local and regional partners. The established language of the public administration is French. As a result, all health and social service institutions provide services in French. The Quebec Health and Social Services Act requires that a number of health services be available in English as well, and that interpretation be made available in other languages (Information sur le ministère de la Santé et des Services sociaux, n.d.). Despite this act, only three CIUSSS center routinely provide services in English (CIUSSS du Centre-Sud-de-l'Île-de-Montréal, 2016).



Through CIUSSS or CISSS, family caregivers of older adults can access many of the services (e.g. home care services and public day programs) they need in their local areas; however, some people directly contact non-profit community organizations that provide social services, such as the YMCA or the Alzheimer Society of Montreal instead of accessing their CISSS or CIUSSS. Depending on the types of programs and specific criteria, clients may be asked to pay a fee when they access services in non-profit community organizations. As mentioned above, not all agencies in Montreal provide services in both English and French. However, some agencies provide services in several languages; the Cummings Jewish Centre for Seniors, for example, provides services in English, French, Yiddish and Hebrew.

Sample and Recruitment

Based on the structure of the health and social service system in Montreal, a list of potential agencies to contact was compiled during the data collection stage of the dissertation proposal. After obtaining approval from the Research Ethics Board at McGill University, formal letters and emails were sent to request permission to conduct a survey with clients to over 40 Health and Social service agencies (as well as religious organizations) located in Montreal, Canada. In the first three weeks of the data collection periods, no agencies replied to the emails; however, reminder emails were sent several times. In the event that the lack of response was due to a lack of time on the part of the agency personnel, the researcher occasionally dropped by agencies to talk with directors or service providers. Despite a lack of response demonstrated by the majority of staff members in various agencies, some staff were willing to have meetings with the researcher. After repeated communication with numerous social and health agencies, some agencies permitted potential participants to be recruited in their centers. When the health and social service agencies, as well as religious communities, acquiesced, a day for survey administration was scheduled.



Multiple types of recruitment strategies were used while attempting to recruit participants in person. First, the researcher attended programs, caregiver meetings or other events in health and social agencies as well as religious communities in which the purpose of the study was briefly introduced, and the process of the survey was explained to the participants. Second, agencies were asked to put the study flyer (see Appendix C), on their bulletin boards and used newsletters in agencies to advertise the study. Lastly, the researcher asked participants to discuss the study with other family caregivers or people who might know family caregivers in their social network. Over half of the participants in this study were self-referred in response to a word-of-mouth referral by participants who completed the survey or by someone who had heard about the study.

When the participants agreed to complete the survey, the researcher made an appointment to meet them in person. The participants chose a place where they wanted to meet (e.g. community agencies, participants' house, participants' workplaces, and coffee shops). Occasionally, participants were interested in completing the study at the time of recruitment (on site). At such times, participants were presented first with a consent form (see Appendix A) and then with the survey (see Appendix B). The surveys were then completed at that time. Participants who needed to ask for help regarding the survey were assisted by: the researcher, staff, or colleagues of the researcher. The survey took 25-35 minutes to complete. Structured questionnaires were used in data collection and were provided in English or French. The questionnaires were translated into French by a professional translator and back-translated into English by another Canadian French speaker. Participants chose the language they preferred to complete the questionnaires in. Before the data collection began, potential subjects and experts who research caregivers or provide services for caregivers of older adults were pretested with the questionnaire for evaluation.



The data collection began during August 2017 and was completed in the last week of January 2018. For this study, 102 participants completed their questionnaires without missing any answers. The lack of missing data is likely due to both the understanding participants had about the importance of this dissertation study, and due to the availability of the researcher for answering any questions the participants might have had. The SPSS 24.0 analysis software was employed to analyze participants' responses to the survey questions. Each study in this dissertation required differing measures and analyses as each had unique research questions. The specifics of data analysis for each study will be described in chapters 2, 3, and 4.

The remaining sections of this dissertation are organized as follows: Chapter 2 presents the first paper, which examines the predictors of unmet services for health and social services among minority family caregivers of older adults. Chapter 3 contains the second paper, which explores the relationship between cultural incompatibility in health and social settings and satisfaction with services among minority family caregivers of older adults. Chapter 4 presents the third paper, which examines the relationship between daily discrimination and health and social service use among minority family caregivers. Chapter 5 contains a summary of the dissertation's main findings, strengths, limitation, and implications.



Chapter 2. Ph.D. Dissertation Study 1:

Predictors of Unmet Needs in Health and Social Services among Minority Family

Caregivers of Older Adults.

Eunyoung Lee School of Social Work

McGill University



Abstract

Background: Minority family caregivers rarely use health and social services despite experiencing difficulties in supporting their older adult relatives in the community. This trend may result in heightened levels of unmet need amongst minority family caregivers. Yet the population characteristics and an environmental factor that may exacerbate unmet service needs for minority family caregivers have remained relatively unexplored. Further, the extent to which unmet needs are experienced by minority caregivers (in particular aspects of the health and social service system) are rarely examined.

Research Questions: This study has two research questions: 1) what types of unmet health and social service needs do minority family caregivers report? and 2) are specific population characteristics and cultural incompatibility associated with unmet needs among minority family caregivers?

Methods: A cross-sectional survey was conducted with 102 racial- and ethnic-minority family caregivers of older adults with chronic illnesses in Montreal, Canada. The sample was drawn from communities and religious organizations, informal referrals, social service providers, and on site recruitment by the principal investigator. In this study, the Andersen Behavioral model (1995) was used. Predictors were derived from the four major components of the model (e.g. predisposing, need, enabling, and environmental factors). The outcome variable was unmet needs. Bivariate analysis and hierarchical multiple regression were conducted using SPSS 24.

Results: This study found that some population characteristics and an environmental factor were significantly associated with unmet needs among minority family caregivers. To be specific, a lower number of care recipient medical issues were associated with overall unmet needs and unmet needs in professional help and direct services among minority family caregivers. Another



important finding from the study is that a higher level of cultural incompatibility, lack of ethnicspecific services use, and a lower level of connection to religious communities coherently predicted unmet needs among minority family caregivers.

Conclusion: Findings of this current study suggest that cultural incompatibility, lack of ethnic-specific services use, and religious connections may variously impact caregivers' perception of their unmet needs with regards to health and social services. To better address various types of needs among caregivers, service agencies and policy makers should consider using alternative methods (such as collaborating with community experts and considering use assessments of caregiver needs) to promote better access to services and thus reduce caregivers' unmet service needs in health and social service settings. In doing so, minority family caregivers may not only reduce their own care burden, but also consequently provide better care for their loved ones in the community.



Introduction

Over eight million Canadians are caregivers for community-based family members or friends to older adults with age related functional limitations (Sinha, 2013; Turcotte, 2013). This number is likely to increase as the population ages and as policies continue to emphasize "aging in place" which places a priority on an older adult's reception of various services and care at home instead of in long-term care facilities (Morley, 2012). While over 80% of community-based caregiving of older adults is provided by families, minority caregivers (i.e. racially and ethnically diverse caregivers (Statistics Canada, 2016) often provide more intensive caregiving than non-minority family caregivers (Rote & Moon, 2016). Hence, it is incumbent on service providers and policy makers, to ensure needs for services are met as this is an important element of service access.

Previous research in North America has uncovered that non-minority family caregivers access more health and social services than minority family caregivers (Lee & Smith, 2012; Woodward, 2011). Furthermore, minority family caregivers who utilize services are more likely to be dissatisfied with service available than their non-minority counterparts (Sorkin, Ngo-Metzger, & De Alba, 2010; Wolff, Spillman, Freedman, & Kasper, 2016). In an effort to improve satisfaction with services among minority caregivers, several studies have explored barriers to service use among these populations (Ahmed et al., 2016; Stewart et al., 2011; Thomson, Chaze, George, & Guruge, 2015). Findings suggest that these caregivers feel the services provided are inadequate and, in some cases, this deters use. In addition, findings indicate that lack of English language proficiency, mistrust of services, limited knowledge of the health and social service systems, and experiences of discrimination pose unique barriers to service access among racially and ethnically diverse caregivers (Ahmed et al., 2016; Edge & Newbold,



2013; Henderson & Kendall, 2011; Sorkin et al., 2010; Stewart et al., 2011). This suggests that the current health and social service system may not be meeting the needs of racially and ethnically diverse family caregivers of older adults in North America. Those minority family caregivers deemed particularly vulnerable to experiencing unmet needs in American studies include caregivers with low incomes, caregivers who had a lack of support from others, caregivers who experienced mental or physical health issues, and caregivers whose care recipients suffer from physical and behavior issues (Beach & Schulze, 2017; Casado, van Vulpen, & Davis, 2011; Lam et al., 2011; Li, Kyrouac, McManus, Cranston, & Hughes, 2012).

In recent years, studies have sought to examine various factors that may reduce experiences of unmet need among marginalized groups such as immigrants and caregivers. A link between a lack of ethnic specific services and difficulty in accessing mental health services was noted by Sadavoy, Meier, and Ong (2004). Most noteworthy is the work of Lai and Surood (2010) who have noted that services deemed culturally incompatible may limit experiences of service use amongst South Asian populations in Canada. By exploring an expansive list of service-related factors, Lai and Surood (2010) have uncovered some important aspects of service delivery that if addressed could more consistently meet the needs of South Asians in Canada. As a lower level of service use has been linked to a higher level of unmet needs (Urbanoski, Inglis, & Veldhuizen, 2017), the current study builds on the work of Lai and Surood (2010) and Sadavoy and colleague (2004) by exploring the types of unmet service needs expressed by racially and ethnically diverse caregivers in Canada and exploring factors that may impede or support unmet service needs among this expanding group of Canadian family caregivers.



Conceptual Framework

This study uses Andersen's Behavioral Model (Andersen, 1995) to examine predictors of unmet needs for minority family caregivers accessing health and social services (Casado et al., 2011; Marshall, 2011; Smith, 2003). The Andersen model suggests that predisposing factors, need factors, enabling factors, and environmental factors work together to predict unmet service needs for a variety of populations (Andersen & Newman, 2005). The model has been applied to racially and ethnically diverse populations (Kim, Hong, & Noh, 2018; Hochhausen, Le, & Perry, 2011; Shibusawa & Mui, 2010) and holds promise in capturing the types of factors that could predict unmet needs for minority family caregivers who support their older adult care recipients in the community.

Within the context of the model, predisposing factors represent characteristics of the service user (e.g. gender, age) which may render them more vulnerable to unmet service needs. People who have unique characteristics are more likely to have unmet needs even though those characteristics may not lead to unmet needs directly (Li et al., 2012). For example, the caregiving literature has shown that female caregivers are more likely to have unmet needs compared to male caregivers when providing care for their loved ones (Casado et al., 2011).

Need factors, which are also considered predictors in the model, are those circumstances that are indicative of a need for a given health and social service. These factors can be captured using objective measures (e.g. number of chronic conditions) or subjective measures (e.g. self-perceived health). Within the context of the model, persons who have more needs to begin with may be more vulnerable to unmet needs when engaging in health and social services - in part because their needs may be harder to meet in the context of service limitations (Andersen & Newman, 2005).



In the caregiving literature, both care recipient functioning and caregiver functioning have been considered when examining need factors (Kim et al., 2018; Scharlach, Giunta, Chow, & Lehning, 2008). Specifically, recent studies on unmet needs have found that care recipients' physical functions are significantly associated with caregivers' unmet service needs (Casado et al., 2011; Li et al., 2012; Stirling, Andrews, Croft, Vickers, Turner, & Robinson, 2010). Care recipient functioning is a good indication of caregiver needs as the lower the functioning, the more demands there are on the caregiver and hence the more need the caregiver has for support and assistance. As a result, care recipients' medical issues were quantified and used as a need variable since they can be used to measure functional limitations and to predict caregiver burden.

Third, enabling factors are individual or structural resources that may protect people from experiencing unmet needs when engaging with health and social services (Andersen, 1995; Andersen & Newman, 2005). When enabling resources are not available to people to access health and social services, they are more likely to have unmet needs (Andersen & Newman, 1973). For example, when family caregivers need services but do not have transportation to access services in a hospital, they are more likely to have unmet medical service needs compared to those who need services and have a car. Previous studies have shown that enabling factors have been found to protect caregivers from unmet service needs; for example having access to a car, feeling connected to religious communities, caregiver's employment status, and having familiarity with the health and social system (Moon, Rote, & Haley, 2018; Scharlach et al., 2008). Therefore, the current study considered caregiver's employment status, transportation, access to ethnic-specific services, familiarity with the Canadian health and social system, and connection to a religious community as enabling variables.



Lastly, aspects of the health care system, which are a part of the larger environment within which caregivers function, may affect met/unmet needs for minority family caregivers. Specifically, the health care system in the model consists of the "policies, resources, organization, and financial arrangements influencing the accessibility, availability, and acceptability of medical care services" (Phillips, Morrison, Andersen, & Aday, 1998 p. 574). Despite the importance of equitable access to health and social services, minority family caregivers face difficulties accessing health and social services because of lack of cultural/linguistic services, or programs with religious components which may be indicators of unmet service needs.

Based on the work of Lai and Surood (2010), an important factor may protect racially and ethnically diverse caregivers from experiencing unmet service needs: access to services considered to be culturally compatible (which fits the definition of an environmental factor). Another study (Sadavoy et al., 2004) highlights the importance of another factor which may impact unmet service needs: access to ethnic-specific services (which fits the definition of an enabling factor). Therefore, the current study included these two factors as environmental and enabling factors in the behavior model. Using an adapted version of the model to explore the extent to which minority family caregiver population characteristics (e.g., predisposing, need, and enabling factors) and an environmental factor (e.g. health care system which is considered as cultural incompatibility) are associated with met/unmet needs was seen as pertinent for the current study. Exploring each of the four constructed factors in the current study allows researchers and service providers to identify the contribution of minority family caregivers' unmet health and social service needs. Findings from this study should provide better insights



into how to tailor health and social service provision to reach the most minority family caregivers.

Research Questions

The current study sought to answer the following research questions: 1) what types of unmet health and social service needs do minority family caregivers report? and 2) are specific population characteristics and cultural incompatibility associated with unmet needs among minority family caregivers?

Methods

Design

This study used a cross-sectional survey design to explore the impact of population characteristics and an environmental factor on unmet needs among minority family caregivers of older adult relatives with chronic illnesses in Canada.

Sample

The sample for this study included 102 racial and ethnic minority family members of community-residing older adults (65+) living with degenerative physical and cognitive chronic conditions that required ongoing support. Eligible participants: (1) were 21 years or older; (2) had enough language capacity to complete the questionnaires in English or French with some assistance; (3) were either immigrants to Canada from non-French or English speaking countries or members of ethnic or racial minority groups; (4) were primary unpaid caregivers of persons 65+, residing in the community and requiring assistance with at least two ADLs/IADLs; (5) had used or tried to use health and social services to support their caregiving within the last 12 months; and (6) lived in Montreal.



Data Collection

Using purposive and snowball sampling techniques, a sample of racial and ethnic minority family caregivers was recruited at several health and social service agencies and community and religious organizations located in Montreal, Canada. Specifically, the researcher attended programs, caregiver meetings, and other events in order to briefly introduce the survey and consent process to potential participants. When potential participants agreed to participate in the survey, the researcher used interviews to identify if the caregiver participants were eligible based on inclusion criteria.

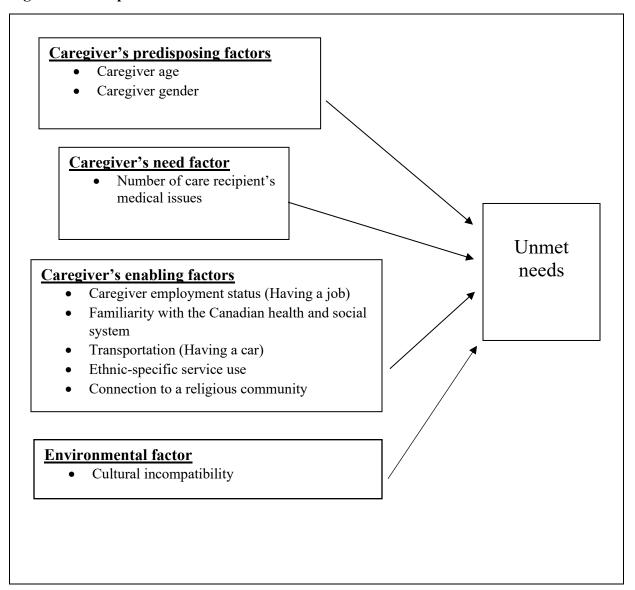
The survey was available in English and French. The French version of the survey was prepared using forward-translation and back-translation by two different professional translators. The participants filled out the questionnaire with the help of the researcher when needed on site. The questionnaire took 30 to 40 minutes to complete depending on the caregiver's language proficiency. After full written consent was obtained, caregiver participants answered questions regarding caregiver and care recipient socio-demographic information and health and social service use. The Research Ethics Board at McGill University approved the research protocol (REB-2 #141-0817).

Measurement

By using Andersen's behavioral model (Andersen, 1995), this study examined what predisposing, need, enabling, and environmental factors facilitated or hindered met caregiver service needs. All selected variables and their perceived relationship with met/unmet needs are represented in Figure 1 and described in more detail below.



Figure 1. Conceptual Framework



Dependent Variable

Met/unmet service needs of participants were measured by capturing the extent to which a caregiver's perceived need for services matched with their actual use of health and social services. Fourteen major elements of health and social services were identified based on the literature concerning elderly care services and family caregiving. Broadly the 14 listed services related to (1) medical care, which included in-home medical services, general medical clinics,



and outpatient specialized clinics; (2) respite care, which included respite care-day center, respite care-nursing home or residence, and respite care-in home; (3) professional help, which included caregiver support group, caregiver educational sessions, counseling services, and legal and financial information; (4) direct services, which included transportation services, home maker services, and senior centers for recreational and social programing. More specifically, participants were asked to indicate (1) which of the 14 health and social services they needed to support their caregiving over the past 12 months and (2) which of those services they used. A new variable was created based on the responses to service use and needs given by the participants. For example, if a participant answered that they needed and used respite care services, their need was considered a met need (coded as 0). Conversely, if a participant answered that they needed respite care services, but did not use them, their need was considered an unmet need (coded as 1). This study calculated each participant's number of met and unmet needs, providing a score ranging from 0 to 14. A higher total score indicated that caregivers had a higher level of unmet needs.

Independent Variables

Predisposing Variables

In studies of the general population, race and/or immigration status have been used as predisposing variables; however, all family caregiver participants in the current study were marginalized based on their race and ethnicity and thus race and immigration status could not be used as predisposing variables. Instead, caregiver age and gender were selected as predisposing variables in this study. In previous literature, age and gender were also considered important predisposing factors as both have been found to predict unmet need for diverse racial and ethnic caregivers (Casado et al., 2011; Chen & Thompson, 2010).

Need Variable

Common need variables previously used with Andersen's health behavior model include: number of chronic diseases, caregiver recipient's cognitive impairment, and/or caregiver burden (Kim et al., 2018; Scharlach et al., 2008). These need variables, however, have produced mixed results when predicting service use or quality of life. For the current study, only the number of the care recipient's medical issues was utilized as a need variable as this can be said to indirectly measure functional limitations and caregiver burden.

Based on the literature on older adults' care services and family caregiving (Casado et al., 2011; Jaul & Barron, 2017; Sibley, Voth, Munce, Straus, & Jaglal, 2014), 12 major types of medical conditions among older adults were identified: Cancer; Chronic heart problems (i.e. high blood pressure, congestive heart failure); Chronic obstructive pulmonary disease (COPD) or Lung disease; Diabetes; Kidney problems; Arthritis, Osteoporosis, or Rheumatism; Partial or complete paralysis; Visual or hearing impairment; Diagnosed depression or anxiety; Dementia; Parkinson's disease; and other. From the list of 12 medical issues, caregivers were asked to list the total number of medical issues experienced by the care recipient, each of which was measured and accounted for. The total value of the scale was calculated by the sum of the scores of all 12 items; scores ranged from 0 through 12. A higher total score indicated that care recipients had a greater number of medical issues.

Enabling Variables

Five variables were used as caregiver enabling factors: ethnic-specific service use, familiarity with the Canadian health and social care system, transportation (i.e. having a car), caregiver's employment status (i.e. having a job), and connection to a religious community. The factors listed above have been found to affect either service use or unmet needs among racially and ethnically diverse people (Burgess, Ding, Hargreaves, Van Ryn, & Phelan, 2008; Lai &



Surood, 2010; Spencer, Chen, Gee, Fabian, & Takeuchi, 2010). For example, having a car may allow a caregiver to have more access to caregiver programming.

Ethnic-specific service use and having a car were measured dichotomously (1 = Yes, 0 = No). Familiarity with the Canadian social and health care system was measured (0 = Not at all, 1 = A little bit, and 2 = Very much). Caregiver's employment status was measured by asking "Are you currently working?" The responses were provided from 1 to 3 (1 = Yes, full-time, 2 = Yes, part-time, 3 = No). Connection to religious community was measured by asking, "How often do you usually attend religious services? The response was measured from 1 to 6 (1 = Never, 2 = Less than once a year, 3 = A few times a year, 4 = A few times a month, 5 = At least once a week, 6 = Nearly every day). A higher total score indicated that caregivers had a greater connection to religious communities.

Environmental Variable

Cultural incompatibility was used as an environmental variable for this study. To measure cultural incompatibility, this study used the Cultural Incompatibility subscale from the Service Barriers scale (Lai & Surood, 2010). The Cultural Incompatibility subscale (five items) captures whether service agencies provide cultural and linguistic services for minority family caregivers. For example, one of the questions was "The professionals there do not speak your language." Participants had the option to respond with Yes (1) or No (0). The total value of the scale was calculated by the sum of the score of all 5 items; scores ranged from 0 through 5. A higher score indicated that the respondent experienced a higher level of cultural incompatibility. The reported reliability of the cultural incompatibility subscale was $\alpha = 0.84$ (Lai & Surood, 2013). In the present sample, Cronbach's alpha for this subscale measure was shown to be satisfactory ($\alpha = .80$).



Data Analysis

All analyses were performed using SPSS statistics program version 24.0. Overall, analysis of variance, Pearson's correlation analysis, and multiple linear regression analysis were performed. The data analyses were done in three phases. First, descriptive statistics were utilized for all variables to offer a basic understanding of the caregivers' characteristics. Second, Pearson correlations were conducted to test for bivariate associations among all variables. No variables were excluded from the multivariate analyses based upon the bivariate results. Lastly, a hierarchical multiple linear regression analysis was used to test for the impact of predictors on caregivers' total unmet needs. To gain a more specific understanding of how particular factors relate to a specific area of service need, a hierarchical multiple linear regression analysis was also used to test for the impact of predictors on four separate types of caregivers' unmet needs (e.g. respite care, medical care, professional help, and direct services). The steps of the current study's analysis, guided by four components (i.e. predisposing, need, enabling, and environmental) of the Andersen behavioral model (Andersen, 1995), were entered in the following sequence: (1) the predisposing predictors were entered in Block 1; (2) the caregivers' need variable was entered in Block 2; (3) the caregiver' enabling variables were entered in Block 3; and (4) the environmental variable was entered in the final block. Some studies using the Andersen Behavioral Model entered the predisposing, the enabling, and then the need variables in that order for regression analysis; however, other studies entered predisposing, need, and then enabling variables to illustrate the purpose of their studies or to fit the preference of the authors (Casado et al., 2011; Hirshfield, Downing Jr, Horvath, Swartz, & Chiasson, 2018; Li, Nong, Wei, Feng, & Luo, 2016). As environmental factors were not included in previous studies, the order in which the environmental variables were included in analysis has no precedent. This current study entered the predisposing variables, needs, enabling, and environmental variables in



that order for analysis. The main reason was that this study tested whether the incorporated enabling and environmental factors impact unmet needs, while controlling for predisposing and need variables in the model. In terms of analysis, this technique enables the researcher to easily report explained variance for types of factors that influence unmet health and social service needs. All assumptions were met for hierarchical regression, including no multicollinearity between variables. The level of significance was set at 0.05.

Results

Descriptive Information of Sample and Study Variables

Table 1 presents socio-demographic descriptions of caregiver participants and study variables. One hundred and two participants completed the survey. Among the participants, 71 caregivers were female (69.6%). Participants had a mean age of 60 and ranged in age from 26 to 88 (SD = 16.51). Over half of participants reported no ethnic-specific service use (n =70, 68.6 %) and participants reported a high level of cultural incompatibility (M = 3.72, SD = 1.62; range 0-5). Among the participants, sixty-seven participants reported having a car (65.7%). In addition, participants reported a high level of familiarity with the Canadian health and social care system (M = 2.44, SD = .60; range 1-3). 41 of 102 participants were employed either in full-time jobs (28.4 %) or part-time (17.6 %). In addition, the average connection to religious communities was reported to be between a few times a year and a few times a month (M = 3.49, SD = 1.69; range 1-5). Care recipients had between two and three medical issues (M = 2.80; SD = 1.50; range 1-7).



Table 1. Descriptive Characteristics of Sample and Study Variables (N=102)

	Mean (SD)	n (%)
Caregiver age	60.01 (16.51)	
26-59 Years		51 (50.0)
60-69 Years		18 (17.6)
70-79 Years		16 (15.7)
80+ Years		17 (16.7)
Caregiver gender		,
Male		31 (30.4)
Female		71 (69.6)
Caregiver employment status		, ,
Yes, Full-time (1)		29 (28.4)
Yes, Part-time (2)		18 (17.6)
No (3)		55 (53.9)
Ethnic-specific service use		
Yes		32 (31.4)
No		70 (68.6)
Having a car		, ,
Yes		67 (65.7)
No		35 (34.3)
Connection to a religious community	3.49 (1.69)	, ,
Never		20 (19.6)
Less than once a year		12 (11.8)
A few times a year		18 (17.6)
A few times a month		12 (11.8)
At least once a week		30 (29.4)
Nearly every day		10 (9.8)
Familiarity with the Canadian health	2.44 (0.60)	
and social care system		
The number of care recipient's medical	2.80 (1.50)	
issues		
Cultural incompatibility	3.72 (1.62)	

Note *SD, Standard Deviation

Distribution of Caregiver's Service Need, Use and, Unmet needs

Table 2 summarizes 14 health and social services based on needs, use, and unmet needs among minority family caregivers. Most participants reported the need for general medical clinic (n = 100), home maker services (n = 99), respite care-in home (n = 97), caregiver support group



(n = 96), and counseling services (n = 93) respectively. However, with the exception of medical services, these services were less likely to be used than other services, suggesting that they represent areas in which service needs were not met. Participants also reported that they frequently use (n = 58) and need (n = 71) senior centers for social activities, which indicated met needs. While financial and legal information was less frequently reported as used, when these services were needed, they were the area of service least likely to be met.

Table 2. Distribution of Caregivers' Health and Social Service Need, Use, and Unmet Needs

	Health and social service need	Health and Social Service Use	Unmet needs
	Need n	Use n	Unmet need n
Caregiver support group	96	20	76
Financial information	88	18	70
Legal information	85	21	64
Home maker services	99	37	62
Counseling services	93	31	62
Caregiver education sessions	81	24	57
Respite care-in home	97	42	55
Transportation	86	52	34
Respite care-Day center	62	40	22
Respite care-Nursing home	45	28	17
In-home medical services	87	69	18
Senior center	71	58	13
(social/recreational activities)			
Outpatient specialized clinics	69	58	11
General medical clinics	100	97	3



Correlations between Variables

Table 3 illustrates correlations between study variables. The number of the care recipients' medical issues was negatively associated with total unmet needs (r = -.33, p < .01), unmet needs in professional help (r = -.29, p < .01), and unmet needs in direct services (r = -.27, p < .01). Cultural incompatibility was statistically and positively associated with total unmet needs (r = .17, p < .05) and unmet needs in professional help (r = .22, p < .01). Furthermore, caregivers' having a car (r = -.23, p < .05) and caregivers' use of ethnic-specific services (r = -.22, p < .05) were statistically and negatively associated with unmet needs in professional help. Lastly, caregivers' age (r = -.21, p < .05), familiarity with the Canadian health and social care system (r = -.31, p < .01), having a job (r = -.28, p < .01), and connection to a religious community (r = -.27, p < .01) were statistically and negatively associated with unmet needs in direct services. However, no variables statistically correlated with unmet needs in respite care and in medical care.



Table 3. Correlations among Study Variables

1 able 3. Correlations amo	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Caregiver age		10	01	.10	11	.18	.02	.58**	00	08	.08	.06	21*	07
2. Caregiver gender		_	.13	.06	01	01	07	05	05	.11	.06	10	02	01
3. CR's medical issues				.10	0.9	09	.06	.07	05	05	.01	29**	27**	33**
4. Cultural incompatibility					.10	12	15	05	.01	.10	.09	.22**	12	.17*
5. Using ethnic-specific services						00	05	05	.08	11	.05	22*	.10	15
6. Familiarity with the health and social care							.15	.07	03	07	.01	06	31**	19
system 7. Having a car							_	17	10	.01	.11	23*	.11	10
8. Having a job									02	03	02	03	28**	15
9. Connection to a religious community										07	08	00	27**	19
10. Unmet needs in respite care											.12	.09	.25*	.59**
11. Unmet needs in medical care												16	.22*	.26**
12. Unmet needs in professional help												_	05	.70**
13. Unmet needs in direct services													_	.52**
14. Total unmet needs														

Note N=102; *p < .05; **p < .01



Predictors of Unmet needs

Table 4 summarizes the results of the hierarchical multiple linear regression analysis examining the relationship between factors (e.g. predisposing, need, enabling, and environmental) and unmet service needs. Hierarchical regression analyses were conducted separately for four types of unmet needs (e.g. respite care, medical care, professional help, and direct service) and total unmet needs. According to bivariate correlation analysis (See Table 3), none of the variables were significantly associated with unmet needs for specifically respite care, and medical care. Thus, no regression analysis was conducted for predicting unmet needs for respite care, and medical care.

Total Unmet Needs

In the first model, the predisposing variables (e.g. caregiver age and gender) accounted for 5 % of the variation in total unmet needs, F(2, 99) = .23, p = .79. The second model, when the caregiver need variable was included, explained an additional 7.8 % of the variation in total unmet needs, F(3, 98) = 2.95, p = .04. Specifically, a higher level of total unmet needs were predicted by a lower number of care recipients medical issues (b = ..33, p = .00, 95% CI [-.56, -.10]). The third model, when the enabling factors were included in the regression model, explained an additional 12 % of the variance in total unmet needs, F(8, 93) = 2.91, p = .00. Specifically, a higher level of total unmet needs were predicted by caregivers with unfamiliarity with the Canadian health and social care system, b = -.78, p = .03, 95% CI [-.1.47, -.92] and a lower level of connection to a religious community, b = -.26, p = .03, 95% CI [-.1.47, -.02]. The last model, when the environmental variable was included, explained an additional 3.2 % of the variation in total unmet needs, F(9, 92) = 3.09, p = .00. Specifically, a higher level of total unmet needs were predicted by caregivers with a higher level of cultural incompatibility, b = .25,



p = .04, 95% CI [-.00, -.50]. However, total unmet needs were not predicted by the predisposing variables, caregiver's employment status, having a car, and ethnic-specific services use, when the environmental factor was added in the final model.

Unmet Needs: Professional Help

In the first model, the predisposing variables (e.g. caregiver age and gender) accounted for 1.1 % of the variation in unmet needs in professional help, F(2, 99) = .57, p = .60. The second model, when the caregiver need variable was included, explained an additional 6 % of the variance in unmet needs in professional help, F(3, 98) = 2.36, p = .07. Specifically, a higher level of unmet needs in professional help were predicted by a lower number of care recipients medical issues (b = -.20, p = .02, 95% CI [-.37, -.04]). The third model, when the enabling factors were included, explained an additional 11 % of the variance in unmet needs in professional help, F(8, 93) = 2.48, p = .02. Specifically, caregivers' lack of ethnic-specific service use, b = -.73, p = .03, 95% CI [-1.30, -.09], and caregivers' lack of transportation, b =-.79, p = .02, 95% CI [-1.43, -.15] were significantly associated with a higher level of unmet needs in professional help. The last model, when the environmental variable was included, explained an additional 4.2 % of the variation in unmet needs in professional help, F(9, 92) =2.86, p = .00. Specifically, a higher level of unmet needs in professional help were predicted by caregivers with a higher level of cultural incompatibility, b = .21, p = .03, 95% CI [.02, .40]. However, the predisposing variables, caregivers' employment status, familiarity with the Canadian health and social care system, and connection to a religious community were not statistically associated with unmet service needs in professional help in the final model.

Unmet Needs: Direct Services



In the first model, the predisposing variables (e.g. caregiver age and gender) accounted for 4.6 % of the variation in unmet needs in direct services, F(2, 99) = 2.36, p = .10. The second model, when the caregiver need variable was included, explained an additional 4.4 % of the variance in unmet needs for direct services, F(3, 98) = 3.21, p = .03. Specifically, a higher level of unmet needs in direct services were predicted by a lower number of care recipients medical issues (b = -.10, p = .03, 95% CI [-.19, -.01]). The third model, when the enabling factors were included, explained an additional 26 % of the variance in unmet direct service needs, F(8, 93) =6.15, p = .000. Specifically, caregivers with a lower level of connection to a religious community, b = -.16, p = .000, 95% CI [-.24, -.08], having a job, b = -.19, p = .04, 95% CI [-.39, -.01], and unfamiliarity with the Canadian health and social care system, b = -.50, p = .000, 95% CI [-.75, -.27] were significantly associated with a higher level of unmet needs in direct services. In the third model, the predisposing variables, ethnic-specific services use and having a car were not statistically associated with unmet needs in direct services. In the final model, when the environmental variable was included, explained an additional 8 % of the variation in unmet direct service needs, F(9, 92) = 5.60, p = .000. Specifically, a higher level of unmet needs in direct services were not predicted by caregivers with a higher level of cultural incompatibility, b = -.05, p = .29, 95% CI [-.14, .04]. The predisposing variables, ethnic-specific services use, and having a car were not statistically associated with unmet needs in direct services, when the environmental factor was added in the final model.

In summary, this effect could be influenced by four main factors: The number of care recipients' medical issues, cultural incompatibility, familiarity with the Canadian health and social care system, and connection to a religious community. The number of care recipients' medical issues negatively correlated with the total unmet needs and the unmet needs in direct



services. A higher level of cultural incompatibility among caregivers was significantly associated with a higher level of both total unmet needs and unmet needs in professional help. An unfamiliarity among caregivers with the Canadian health and social care system and a lower level of connection to a religious community among caregivers were significantly associated with a higher level of both total unmet needs and unmet needs in direct services.



Table 4. Hierarchical Linear Regression Analyses of Unmet Needs

	Factors		Unm	et needs	:		Unm	et needs:	,		7	Total		
		Professional help					Direct services				Unmet needs			
		В	β	R^2	Adjusted R ²	В	β	R^2	Adjusted R ²	В	β	R^2	Adjusted R ²	
1	Predisposing factors			.01	01			.05	.03			.01	02	
-	Caregiver age	.00	.05			01	21*			01	07			
	Caregiver gender	31	09			08	04			09	02			
2	Need factor			.07*	.04			.09*	.06			.08*	.06	
-	The number of CR's	20	24*			10	21*			33	28**			
	medical issues													
3	Enabling factors			.18*	.11			.35***	.29			.20**	.13	
-	Ethnic-specific service	73	22*			.23	.13			60	13			
	use Familiarity with the Canadian health and social care system	17	07			50	36***			78	22*			
	Having a car	79	24*			.28	.16			35	08			
	Caregiver employment	23	13			19	19*			43	17			
	Connection to a religious community	02	02			16	32***			23	18*			
4	Environmental			.22**	.14			.35***	.29			.23**	.16	
	factor													
	Cultural incompatibility	.21	.22*			05	09			.26	.19*			

Note N=102; *p < .05; **p < .01; ***p<.001



Discussion

This study explored factors that contribute to unmet needs among racial and ethnic minority family caregiver groups underrepresented in the caregiving literature. To accomplish this, Andersen's Behavioral model of Health Services Use (1995) was applied. Consistent with previous research on service use which indicated the importance of need, enabling, and environmental factors (Casado et al., 2011; Spencer et al., 2010), the overall results of this study found the effects of three of the four types of factors were significantly associated with the unmet needs of minority family caregivers. Of the need factors examined, the number of care recipients' medical issues was found to be significantly associated with unmet needs. Among the enabling factors, caregivers' lack of ethnic-specific services use, a lower level of connection to a religious community, unfamiliarity with the Canadian health and social care system, lack of transportation, and caregivers' employment status were all significantly associated with various types of unmet needs. Finally, a higher level of cultural incompatibility in health and social services, which was used to represent an environmental factor in this study, was found to be significantly associated with unmet needs among minority family caregivers. The impact of these significant connections are discussed below.

Consistent with previous findings on caregivers' unmet needs (Black et al., 2013; Lee, Kearns, & Friesen, 2010), this study found that the unmet needs most commonly reported among minority family caregivers were the services of caregiver support groups, financial and legal information, homemaker services, and counseling services. Family caregivers often face combined demands of caregiving which may make it difficult for these caregivers to attend caregiver support groups or counseling sessions or other needed services. For example, almost half of minority family caregiver participants (46%) in this study reported having jobs and



caregivers reported that their care recipients had multiple medical issues (M = 2.80). Due to these demands on their time, it might be beneficial for caregivers to have the option of receiving these services online or via alternate technology (Lee, 2015; Madara Marasinghe, 2016).

In addition, consistent with the current finding, older adults and their families in the general population who use homemaker services commonly report high levels of unmet need (Desin, Caban-Holt, Abner, Van Eldik, & Schmitt, 2016). One reason for the high levels of unmet need in the area of homemaker services would be that minority family caregivers might have less knowledge how to access this type of services (Kosloski, Montgomery, & Karner, 1999). This is supported by a result from the current study that caregivers who reported a lack of familiarity regarding the location of health and social services indicated a higher level of total unmet needs and unmet needs in direct services. Seemingly, minority family caregivers would benefit from outreach in order to ensure that they are aware of the ways on may access homemaking services and other direct services provided through health and social service networks (Washington, Bean-Mayberry, Riopelle, & Yano, 2011).

A lower number of care recipients' medical issues, which was used to represent caregiver need factor in this study, was significantly associated with a higher level of the total unmet needs and the unmet needs in direct services -a result which is contrary to the principal investigator's expectations. It could be possible that when care recipients have a lower level of medical issues, caregivers might not frequently use services and have a higher level of unmet service needs. In correspondence with the findings of this current study, Black and colleagues (2013) revealed that care recipients with milder physical limitations were associated with unmet needs. However, the findings from previous studies regarding the impact of the numbers of care recipients' medical issues were mixed. Other studies have shown that a higher score on ADL limitations among care



recipients was associated with unmet service needs (Hoogendijk et al., 2014; Li et al., 2012). These mix findings suggest that current research only emphasizes the medical situations of care recipients when it comes to measuring unmet needs. In other words, using care recipient function as an entry point for services may be overlooking caregiver needs for services. Taken together, these findings support the movement towards advocating for offering access to services based on caregiver need rather care recipient function (Black et al., 2013).

Findings of the current study also show that both a higher level of total unmet needs and unmet needs in professional help were predicted by higher levels of cultural incompatibility and lack of experience in using ethnic-specific services. This finding is consistent with similar research on unmet needs and service use, which suggests that ethnic minority clients experience culturally insensitive services such as a lack of interpreters and misunderstanding of the client's culture, which cause a higher level of unmet needs (Boneham et al., 1997; Koehn & Badger, 2015). To reduce unmet service needs for minority family caregivers, we must find a way to encourage minority family caregivers to use agency-based services. The findings of the current study suggest that one way to reduce unmet service needs for minority family caregivers is to improve the cultural compatibility of agencies and tailor the ethnic specific services provided to the minority family caregivers who are the intended recipients of the services. Before attempting to 'improve' said services, it would be beneficial to conduct a needs assessment to determine which culturally compatible services and ethnic specific services would be most frequently utilized by the local minority family caregivers. Another way to improve the accessibility of these services might be to alter the way in which caregivers can access said services. For example, with the professional service, it might be beneficial to offer them online. Services which require direct communication between clients and the professionals (e.g. counseling, legal



and financial services, support groups) might be offered via video conferencing or chat.

Educational modules can also be created and utilized in either self-study tutorials or online classes (Madara Marasinghe, 2016)

Similar to the findings for cultural incompatibility and ethnic-specific services use (Debnam, Holt, Clark, Roth, & Southward, 2012; Sanchez, Dillon, Ruffin, & De La Rosa, 2012), affiliation with a religious community also appeared to play a role in predicting total unmet needs and unmet needs in direct services. The connection to the religious community may reflect that racial and ethnic minority groups tend to use religious communities as a starting point for seeking service. This finding suggests that religious communities (e.g. churches) may function as successful entry points to accessing services and should be used for outreach purposes. Taken together with findings that religious communities and ethnic-specific services may facilitate service access, these findings suggest that arming leaders in these communities with relevant information about health and social services may go far in improving minority family caregiver access to direct services (Nora et al., 1994).

As enabling factors, transportation and caregiver's employment status were negatively associated with either unmet needs in professional help or in direct service among minority family caregivers. Consistent with previous research on service use for older adults (Chiatti, Westerlund, & Ståhl, 2017; Robison, Shugrue, Porter, Fortinsky, & Curry, 2012; Syed, Gerber, & Sharp, 2013), the availability of transportation was found to either enable or limit caregivers' capacities to seek professional help. Hence, improvements to transportation services would likely result in a decrease in unmet needs when it comes to caregivers accessing professional help. For example, more free and unlimited shuttle bus services, which may be provided by either public or private operators, could be helpful for family caregivers who have mobility concerns to access



more health and social services. Provincial agencies can provide taxi vouchers to family caregivers of older adults so caregivers freely use it regardless of any taxi companies.

Additionally, family caregivers who were employed in full-time positions reported experiencing unmet needs in direct services (e.g. senior centers). This is similar to the findings on community-based care services among minority family caregivers of older adults which suggest that family caregivers need more flexibility in the available hours of service settings (Desin et al., 2016; Lee, Wang, Chiou, & Chang, 2009; Robison et al., 2012). In reality, family caregivers usually receive service from community agencies (such as senior centers) during the daytime of weekends; however, employed caregivers might not be able to fully access services during the workday. As such, it would be more helpful for family caregivers to receive services during expanded hours or weekend to provide support and prevent unmet needs.

Limitations of the Study

There are several limitations in this study that should be considered for future research. First, because of generalizability issues, the findings of this current study might be difficult to apply to other racial and ethnic minority family caregivers in other cities or in different countries or minority caregivers who do not have experience in health and social services. Second, because this study used a cross-sectional design, causal relationships cannot be inferred. This is because to infer causality, relationships must be viewed over time so you can see which variable caused the other. This is not possible with a cross-sectional design because the data are only seen at one point in time. Lastly, a validated unmet needs scale should be developed for future research. To capture specific types of unmet health and social service needs, the current study utilized an unmet service needs scale which was developed by the principal investigator. The scale was in the form of checklist-style questions with dichotomous answers (Yes or No). Thus, the internal



consistency (e.g. Cronbach's alpha) for this scale to measure unmet needs could not be calculated. It is noteworthy that the scale was shown to service providers prior to use. The service providers reported that the 14 services listed on the scale comprehensively represented the basket of services offered to community- based caregivers, lending some support for the measure's face validity. Nevertheless, it would be helpful for future researchers to further develop and test the scale to improve validity and reliability.

Implications for Practice and Research

Despite these limitations, the current study findings contribute to the caregiving literature, specifically with regards to the unmet needs of minority family caregivers when it comes to various types of health and social services. To provide better health and social services, two critical points from the study should be addressed in practice and future research: working with community experts and caregivers' need for assessment.

First, when designing services or programs for racially and ethnically diverse minority family caregivers, service agencies should consult community experts who share the minority group's values and beliefs to improve the agencies' cultural compatibility and service provision. The study results indicate that cultural incompatibility (between minority family caregivers and service programs) and caregivers' lack of ethnic-specific service use were found to affect the unmet needs of minority family caregivers. This may be an indication of service barriers which is consistent with previous studies on service use (Kim et al., 2011; Henderson & Kendall, 2011). These studies have shown that racial and ethnic minority groups generally face difficulties with receiving culturally appropriate services in healthcare settings. This indicates that service agencies tend not to pay sufficient attention to ethnic-specific services, including specific needs and cultural responses to ethnic minority clients, and to caregivers' cultural values as well as



language support for racial and ethnic minority groups. More importantly, the more negative experiences that minority caregivers have in health and social services because of various factors (e.g. race/ethnicity, language, culture, and religious), the less benefit caregivers may be getting from services – which, in turn, might cause them to suffer from difficulties while caring for their loved ones living in the community. Therefore, due to reduce cultural incompatibility in health and social services, service agencies might offer a community-developed culturally based training to service providers and create services that reflect the cultural and linguistic needs of clients. For example, service agencies could invite community experts (e.g. religion readers and community activists) who would then teach specific minority client group's cultural values and language to service providers. Alternatively, they could consult on the creation of the course which could then be taught by other instructors. After receiving the training, service providers should possess better knowledge of how best to use culturally appropriate resources in a community and service agencies. In Nora, Daugherty, Mattis-Paterson, Stevenson, and Goodman' study (1994), they show how they developed and conducted a Spanish language and Hispanic cultural competence project though working with school and community partnerships. One of the methods was using community expects. Community experts provided cultural competence training to medical students who would likely work with Hispanic clients in the future. Through evaluation of the program, medical student participants in their study showed improvement in cultural knowledge and skills. Together, while working with community experts, service providers and policy makers can contribute to reducing the unmet needs of minority caregivers by forging better connections between the provider and the clients. As in practice, researchers should consider how a lack of culturally based services affects the unmet needs of minority caregivers and the best method of providing these services to the minority clients.



An effort to increase ethnic-specific service provision should also be considered. Simply implementing more ethnic-specific services would not be the best solution, however – if only due to potential budgeting issues. In reality, it might be difficult for service agencies to implement all services into ethnic-specific version based on clients' language and culture because of limited funding or lack of service users in a particular culture (e.g. only five Korean clients using a community center). Instead, to budget more effectively and to better target the services needed most, service agencies should conduct a needs assessment to determine what kind of ethnic-specific services minority family caregivers need the most. Based on the results of the assessment, the agencies could then create a logical plan for obtaining the prioritized services (e.g. caregiver support group for ethnic minority users) for their minority client groups.

Second, to provide better support for caregivers, service providers should pay attention to assessments of caregiver needs rather than focusing on only care recipients' physical situations. Generally, care recipients with a higher number of medical issues tend to be associated with more unmet needs for caregivers (Hoogendijk et al., 2014; Li et al., 2012). Yet one of the findings from the current study shows that care recipients with fewer medical issues also experienced a higher level of unmet needs than care recipients with more medical issues. This result implies that even if care recipients have fewer medical issues, their caregivers still face difficulties providing care for their loved ones living in a community because caregivers might not be receiving sufficient agency-based services. In many cases, family caregivers receive services according to the Activities of Daily Living (ADL) situation of care recipients, which is assessed by home care workers. Unfortunately, the assessment tends not to reflect caregivers' needs, even if caregivers are the most important resource for care recipients. Not reflecting on caregivers' needs might mean that caregivers have a higher level of caregiving stress (Black at



al., 2013). Ultimately, this system does not help either caregivers or care recipients. Therefore, the needs of family caregivers should be critically considered in order to provide sufficient health and social services (Guberman et al., 2003). In particular, racial and ethnicity minority family caregivers tend to have many difficulties compared to non-minority groups in the caregiving process. Fancey and colleagues (2008) developed caregiver need assessment tools (e.g. The C.A.R.E. Tool), which have led scholars to re-examine and improve assessment methods for caregivers (Seddon & Robinson, 2015; Wells, Bronheim, Zyzanski, & Hoover, 2015). By using these tools, service providers can offer more support by assessing both caregivers' needs and care recipients' situations.

Conclusion

This current study contributes to the caregiving literature on predictors of unmet needs in various types of health and social services among minority family caregivers of older adults with chronic illnesses. Findings of the current study suggest that the total unmet needs, the unmet needs in direct services, and the unmet needs in professional help may be predicted by cultural incompatibility, unfamiliarity with the Canadian health and social care system, a lower level of connection to a religious community, and lack of ethnic-specific service use. To better address various types of needs among caregivers, service agencies and policy makers should consider alternative methods (such as collaborating with community experts and conducting a needs assessment of minority caregiver service needs) to reducing caregivers' unmet service needs in health and social service settings. Through these efforts, minority family caregivers may be able to access and receive more targeted health and social services in order to more easily meet their caregiving needs while caring for their loved ones in the community.



Link between Study 1 and Study 2

The first study titled "Predictors of Unmet Needs in Health and Social Services among minority family caregivers of older adults" focuses on both minority family caregivers' population characteristics and an environmental factor. The first study found, as an environmental factor, cultural incompatibility in health and social services consistently predicted unmet needs among minority family caregivers of older adults. In light of this result, the researcher expected that cultural incompatibility might also be related to service satisfaction-which is another indicator of service access. Building on this foundation, the second study entitled "Is It Too Much to Request Fair Services: Association between Cultural Incompatibility in Health and Social Services and Satisfaction with Services among Minority Family Caregivers" examines how cultural incompatibility influences satisfaction with services among minority family caregivers. The second study of this dissertation also explores whether there are differences among caregivers' racial and ethnic groups in experiences of cultural incompatibility and in overall satisfaction with services.



Chapter 3. Ph.D. Dissertation Study 2:

Is It Too Much To Request Fair Services?: Association between Cultural Incompatibility in Health and Social Services and Satisfaction with Services Among Minority Family Caregivers.

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Abstract

Background: Despite growing evidence that racial and ethnic minority family caregivers in Canada are experiencing impediments to service access due to a lack of support for their cultural values and language, the extent to which these caregivers feel supported and satisfied with the health and social services designed to support them is not known at present.

Aim: The aim of this study is to explore the effects of cultural incompatibility in health and social services on overall satisfaction with services among minority family caregivers of older adult relatives.

Research Questions: This study has two research questions: 1) does cultural incompatibility in the health and social system affect minority family caregivers of older adults' overall satisfaction with health and social services? and 2) does cultural incompatibility in the health and social service system and overall satisfaction with services differ among minority family caregivers of older adults?

Methods: A cross-sectional survey was conducted with 102 racial and ethnic minority family caregivers of older adult relatives residing in Montreal, Canada. The sample recruited from community and religious organizations, informal referrals, social service agencies-based service providers, on site recruitment by the researcher, flyers, and newsletters. Cultural incompatibility (the independent variable) was measured using the Cultural Incompatibility subscale of the Service Barriers scale (Lai & Surood, 2013). Overall satisfaction with services (the dependent variable) was measured utilizing the Impact subscale of the Reid-Gundlach Social Service Satisfaction Scale (R-GSSSS; Reid & Gundlach, 1984). Bivariate analysis and hierarchical multiple regression were conducted by using SPSS 24.

Results: Among the 102 participants, the majority of caregivers were female (70%), and spouses (43 %), had a mean age of 60, and had university level degrees (55.8%). Results of the



hierarchical regression analysis show that after controlling for caregivers' socio-demographic information and care burden, cultural incompatibility impacted overall dissatisfaction with services among minority family caregivers. The study also found that there were no significant differences among various' racial and ethnic minority groups when considering the relationship between cultural incompatibility in health and social services and overall satisfaction with services for minority caregivers.

Conclusion: Based on these findings, it is recommended that hiring more staff with diverse ethnic or racial minority backgrounds, as well as examining the reasons behind caregiver's dissatisfaction with medical service provision are needed to assist minority family caregivers in the effort to increase their access to health and social services.



Introduction

An increase in life expectancy and health service use trends suggest that older adults with chronic conditions and the families who support them will increasingly require health and social service support (Canadian Institute for Health Information, 2011). According to the CIHI (2011), 80% of all care provided to older adults is given by family members who often pay physical, social, financial and emotional costs for delivering this support (Riffin, Van Ness, Wolff, & Fried, 2017; Sun, 2014). The accessibility of services to assist caregivers and relieve caregiver burden is an important part of the effort to keep care recipients living in the community rather than in institutions (Ahmed et al., 2016). Satisfaction with services has been shown to significantly impact service access (Chow, Quine, & Li, 2010; Ngui & Flores, 2006). Within this context, it is incumbent on policy makers and service providers to understand how the basket of services being provided to support older adults is perceived to be supportive by family caregivers (Chow et al., 2010) – particularly racially and ethnically diverse family caregivers who report more negative experiences with health and social services than Canadian born, non-racialized caregivers (Kulwicki, Aswad, Carmona, & Ballout, 2010; Schuster et al., 2012; Thomson, Chaze, George, & Guruge, 2015; Williams, & Sternthal, 2010).

Minority family caregivers describe experiencing problems with service agencies and providers due to insufficient language skills, unfamiliarity with Canadian culture, health and social systems, or differing religious backgrounds (Burgess, Ding, Hargreaves, Van Ryn, & Phelan, 2008; Edge & Newbold, 2013; Ngui & Flores, 2006; Richardson & Norris, 2010; Sorkin, Ngo-Metzger, & De Alba, 2010). Culturally, linguistically, and religiously inappropriate services can make minority family caregivers feel socially isolated and experience a higher level of care



burden when accessing health and social care services (Ahmed et al., 2016; Dias, Gama, & Rocha, 2010).

Like all service systems in Canada, the health and social service systems has been developed with the intent of providing equitable services regardless of race, ethnicity or immigration status. However, some Canadian studies have shown that service agencies and services do not provide enough support for immigrant family caregivers in terms of culture and linguistic service, which cause cultural incompatibility between caregivers, programs and service providers (Stewart et al., 2006). In terms of health and social service use, cultural incompatibility is defined as service agencies lack of cultural/religious sensitivity, limited language capacity, and lack of specialized programs for racial and ethnic minority clients. Surprisingly, cultural incompatibility in health and social services has not been well studied among minority family caregivers. One study which examines service barriers used cultural incompatibility as a subscale to capture service barriers among immigrants (Lai & Surood, 2013). While limited trends in cultural incompatibility have been documented, the relationship between cultural incompatibility in health and social services and satisfaction with health and social services has not been explored.

The majority of the previous studies on service satisfaction either focus on satisfaction with services in the United States, or on the general population of adults who are the recipients of health services rather than adults caring for family members with chronic conditions (Baumann, Le Bihan, Chau, & Chau, 2014; Jang, Kim, & Chiriboga, 2005; López-Cevallos, Harvey, & Warren, 2014; Ngui & Flores, 2006; Perreault, Rousseau, Provencher, Roberts, & Milton, 2012). Given that the service system in Canada differs significantly from service allocation in the U.S and that caregivers in Canada access different services than service recipients in the U.S., the



extent to which racial and ethnic minority family caregivers in Canada feel supported and satisfied with services designed to support them in their caregiving is not known at present. More information regarding the types of cultural incompatibility present in the Canadian health and social service system and its connection with minority family caregivers' satisfaction with services can be used to assist practitioners and policy makers in increasing access to services for this vulnerable population.

Using quantitative methods, the current study examines the relationship between caregivers' perceived cultural incompatibility and their satisfaction with services aimed at supporting both their needs and their care recipients' needs. To address the impact of cultural incompatibility in Canadian health and social services on satisfaction with the services, the following two research questions are addressed in this study: 1) does cultural incompatibility in the health and social service system affect minority family caregivers' overall satisfaction with health and social services? and 2) does cultural incompatibility in the health and social service system and overall satisfaction with services differ among minority family caregivers of older adults?

Theoretical Framework

This study used the Andersen Behavioral Model of Health Service Use (1995) as a conceptual framework to examine the relationship between cultural incompatibility in health and social system and minority family caregivers' satisfaction with services. Andersen's Behavioral model of Health Service Use (1995) is one such model that suggests that environmental and population characteristics affect an individual's health behaviors and subsequent outcome. This model has been applied in the service use literature and tested with a variety of populations (Hong et al., 2019; Marshall, 2011). Specifically, the current study focuses on two major



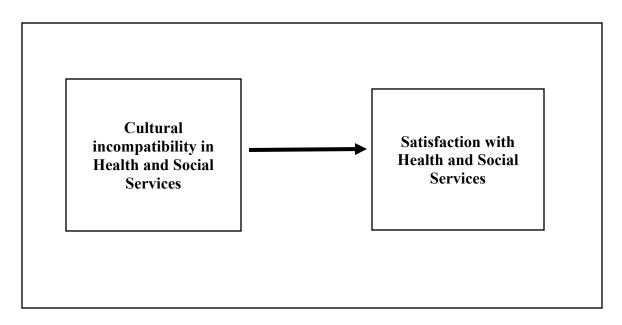
components in the model: an environmental factor (e.g. health care system) and an outcome (e.g. service satisfaction). Cultural incompatibility is a component of the health care system (one of the two environmental factors listed in the Andersen Model; 1995). A lack of cultural/religious sensitivity, limited language capacity, and lack of specialized programs for racial and ethnic minority clients in service agencies are examples of cultural incompatibility in the health care system. Satisfaction with services, on the other hand, is an outcome in the model. Relatively few studies have examined the impact of cultural incompatibility on satisfaction with services.

According to the model, the health service system, as an environmental factor, should affect clients' service satisfaction.

Despite the importance of equitable access to health and social services (supported by Canadian law) qualitative studies on service barriers have found that minority family caregivers face difficulties accessing health services due to a lack of cultural/linguistic services, or programs with religious components (Dias et al., 2010; Edge & Newbold, 2013). The Andersen model indicates that this environmental factor (i.e. cultural incompatibility) may make this population feel more unsatisfied with health and social service than non-minority family caregivers; however, the growing body of caregiving literature regarding minority family caregivers' service barriers has not yet provided enough evidence in support of the application of this model to this population and problem. Therefore, this study seeks to fill this gap by using Andersen model (1995) as a conceptual framework to investigate how minority family caregivers' perceived cultural incompatibility in health and social services affects satisfaction with services (see Figure 1).



Figure 1. Conceptual Framework



Methods

Design

A cross-sectional survey design was utilized to examine the impact of cultural incompatibility on satisfaction with health and social services among minority family caregivers of older adult relatives with chronic illnesses.

Sample

The sample for this study included 102 racial and ethnic minority family members of community-residing older adults (65+) living with degenerative physical and cognitive chronic conditions that require ongoing support. In order to be considered eligible, participants: (1) were 21 years or older; (2) had enough language capacity to complete the questionnaires in English or French with some assistance; (3) were either immigrants to Canada from non-French nor English speaking countries or members of ethnic or racial minority groups; (4) were primary unpaid caregivers of persons aged 65+, residing in the community and requiring assistance with at least



two ADLs/IADLs; (5) had used or tried to use health and social services to support their caregiving within the last 12 months; and 6) lived in Montreal.

Data Collection

Purposeful sampling and snowball sampling were utilized for data collection in this study because they were effective methods for recruiting racial and ethnic minority caregiver participants (Dias et al, 2010; Polli, Batey, Bender, Ferguson, & Thompson, 2013). After obtaining approval from the McGill University Research Ethics Board (REB), the researcher sent formal letters and emails to request permission to conduct a survey with clients from potential health and social service agencies as well as religious communities in Montreal, Canada. The researcher respected all the requirements of the REB and other agencies that reviewed and approved the study proposal and ethics certificate. The researcher attended programs, caregiver meetings, and other events in social and health agencies as well as religious communities, in order to briefly introduce the survey and consent process to the participants. When potential participants showed interest in participating in the survey, the researcher checked their eligibility according to the criteria outlined above.

The survey took 25-30 minutes to complete, depending on participants' language proficiency. Structured questionnaires were used in data collection and provided in English or French. The French version of the questionnaires was prepared using forward-translation and back-translation by two different translators who had French as their mother tongues and fluent English abilities. Participants chose the language of the questionnaires. The participants filled out the printed questionnaire with the principal investigator on site.

Measurement

Dependent Variable



Satisfaction with Health and Social Services. To measure overall satisfaction with the health and social services that caregivers had using to support their caregiving, this study utilized two different scales. First, the Impact subscale taken from the Reid-Gundlach Social Service Satisfaction Scale (R-GSSSS; Reid & Gundlach, 1984) was used to capture participants' overall satisfaction with the combination of health and social services utilized. The Reid-Gundlach Social Service Satisfaction Scale consists of a total of 34 items and three subscales (Relevance, Impact, and Gratification) that assess satisfaction with social services. The purpose of the Impact Subscale was to determine whether the service improved or was helpful for the caregivers' problems. Participants were asked to rate 10 items, presented on a 5 point scale (1= Strongly agree, 2= Agree, 3=Undecided, 4=Disagree, and 5=Strongly disagree). For example, one of the questions was "Things have gotten better since I've been going to the agency". The total value of the scale was calculated by the sum of the scores of all 10 items, with possible scores ranging from 10 to 50. For ease of interpretation, the items were reverse coded to have higher scores indicating a higher level of satisfaction with services. This subscale measure for the impact demonstrated reliability and validity as indicated by Cronbach's alphas of .821 (Reid & Gundlach, 1984). In this study, the Cronbach's alpha for this subscale measure was high (\alpha =.818).

Second, satisfaction with health and social services was measured by capturing what specific types of health and social services caregivers use and their satisfaction with the services. These items were developed specifically for this study. Based on the health and social service programs in the literature and programs and services available for caregivers within the Montreal context of the study, a list of 14 health and social services was identified: counseling service, respite care (i.e. day care center, temporary placement, and in-home respite), caregiver support



group, caregiver education, transportation (e.g. municipally funded adapted transportation or transportation from a community agency), legal information, financial information, medical services (in-home medical services, general medical clinic, or outpatient specialized clinic), home maker services (e.g. household chores, or meals), and use of a senior center for social/recreational activities. Participants were first asked to read the list and consider those services from the list they accessed to support their caregiving. They were then asked to indicate which of the listed services they used in the past 12 months. Participants had the option of responding with Yes or No (0= "No", 1= "Yes"). If they used the services, participants were then asked to indicate "in the past 12 months, how satisfied were you with each of the services used?" Participants had the option to respond with "Unsatisfied (0)", or "Satisfied (1)". This satisfaction scale was utilized only for descriptive purposes (See Table 3).

Independent Variable

Cultural Incompatibility. The Cultural Incompatibility subscale taken from Service

Barriers scale (Lai & Surood, 2013) was used to measure the cultural incompatibility between
health and social service agencies and providers, and minority clients. This subscale appears to
be a good indicator of how health and social service agencies offer services in relation to
minority clients' cultures, languages, and religion -making it appropriate for use with minority
family caregivers. Originally, the Service Barriers scale consisted of a total of 21 items and four
subscales (Cultural Incompatibility, Personal Attitude, Administrative Problem, and
Circumstantial Challenge) that assessed service barriers in health care settings. Specifically, the
Cultural Incompatibility subscale taken from Service Barriers scale has five items. For example,
one of the questions was "Professionals there do not understand your culture". Participants had
the option to respond with Yes or No. The total value of the scale was calculated by the sum of
the score of all 5 items, with possible scores ranging from 0 to 5. A higher total score indicated



that people experienced a high level of cultural incompatibility with service providers and service agencies. The reported reliability of the Cultural Incompatibility subscale was 0.84 (Lai & Surood, 2013). In the present sample, Cronbach's alpha for this subscale measure was shown to be satisfactory (α =.80).

Control Variables

Caregivers' socio-demographic information and care burden were employed as control variables when assessing the relationship between cultural incompatibility and overall satisfaction with health and social services.

Caregivers' socio-demographic information. The information included caregivers age (years), race/ethnicity, gender (1 = Male, 2 = Female, and 3= Transgender), immigration status (1 = Yes, I immigrated to Canada permanently, 2 = No, I was born in Canada, 3 = No, I have temporary status in Canada, and 4 = No, I don't have an official status in Canada), language proficiency (English and French), and familiarity with the Canadian health and social care system (0 = Not at all, 1 = A little bit, and 2 = Very much). Each factor has been shown to impact or have relationships with client satisfaction with services in caregiving or health care literatures (Bauer, Chen, & Alegría, 2010; Chen & Vargas-Bustamante, 2011; Lee, Kearns, & Friesen, 2010). In particular, caregiver language proficiency and familiarity with the system might have relationships with accessing services, and these factors may eventually impact satisfaction or dissatisfaction after accessing services.

Care burden. Care burden was also included as one of the control variables. In the caregiving literature, caregiver burden is a crucial factor for understanding satisfaction with services (Perreault et al., 2012). To measure caregivers' burden, the Burden Scale for Family Caregivers—Short version, (BSFC-S; Graessel, Berth, Lichte, & Grau, 2014) was utilized. The burden scale consists of a total of 10 items that assess family caregivers' subjective burden. The



response was measured from 0 to 3 (0= Strongly disagree, 1= Disagree, 2= Agree, and 3= Strongly agree). The total value of the scale was calculated by the sum of the scores of all 10 items; scores range from 0 through 30. A higher total score indicated that caregivers have a high level of care burden. The reported reliability of the BSFC-S was 0.92 (Graessel et al., 2014), which indicates high reliability. In the present sample, the Cronbach's alpha for this care burden measure was high ($\alpha = .89$).

Data Analyses

All analyses were performed using SPSS statistics program version 24.0. The data analyses were done in four phases. First, descriptive statistics were utilized for all variables to offer a basic understanding of the caregivers' characteristics. Second, analysis of variance (ANOVA) tests were used to examine bivariate differences between caregivers' service satisfaction and cultural incompatibility in health and social services based on their affiliation with a particular racial and ethnic groups (Southeast Asian, East Asian, Black, and White). Third, Pearson correlations were utilized to test for associations among all variables. Lastly, a hierarchical multiple regression analysis was used to examine associations between caregivers' experiences of cultural incompatibility in health and social services and overall satisfaction with health and social services controlling for other variables. This sequential order of entering the variables was based upon typical hierarchical multiple regression guidelines, first entering demographic variables and then entering the second important variables which are more than demographic variables, and then finally entering the main independent variable (Cohen, West, & Aiken, 2014; Petrocelli, 2003). Specifically, caregivers' background characteristics were entered in the first block of the regression model. The care demand variable was added to the regression model's second block. Finally, the cultural incompatibility variable was included in the



regression model's third block. All assumptions were met for hierarchical regression, including no multicollinearity between variables (all Variance Inflation Factors were less than 2 in this study). The level of significance was set at 0.05.

Results

Descriptive Information of Sample and Study Variables

Table 1 presents socio-demographic descriptions of caregiver participants and study variables. Among 102 participants, the majority were female, immigrants (n = 84, 82.4%), with a mean age of 60. In terms of race and ethnicity, the four highest percentages were East Asian (25.5%), Southeast Asian (20.6%), Black (17.7%), and White (15.7%). The mean score for English proficiency was 2.68 (SD = .57; range 1-3) and for French proficiency was 2.43 (SD = .62; range 1-3). Both of these finding indicate that participants in this study had good communication skills in both English and French. In addition, participants appeared to have a high level of familiarity with the Canadian health and social care system (M = 2.44, SD = .60; range1-3). Participants reported a moderate level of care burden (M = 14.39, SD = 6.26; range 0-29), and a medium-to-high level of overall satisfaction with health and social services (M = 33.32, SD = 6.42; range 18-46).



Table 1. Descriptive Characteristics of Sample and Study Variables (N=102)

	Mean (SD)	n (%)
Caregiver age	60.01(16.51)	
26-59 Years		51 (50.0)
60-69 Years		18 (17.6)
70-79 Years		16 (15.7)
80+ Years		17 (16.7)
Caregiver gender		
Male		31 (30.4)
Female		71 (69.6)
Caregiver race/ethnicity		
White		16 (15.7)
East Asian		26 (25.5)
South Asian		2 (2.0)
Black		18 (17.6)
Southeast Asian		21 (20.6)
Latin American		4 (3.9)
Middle Eastern		11 (10.8)
West Asian		2(2.0)
Inuit and Others		2 (2.0)
Language proficiency		, ,
English	2.68 (.57)	
French	2.43 (.62)	
Caregiver immigration status	•	
I immigrated to Canada permanently		84 (82.4)
I was born in Canada		15 (14.7)
I have a temporary status in Canada		3 (2.9)
Familiarity with the Canadian health	2.44 (0.60)	
and social care system		
Care burden	14.39 (6.26)	
Overall satisfaction with Health and	33.32 (6.42)	
Social Services		

Note *SD, Standard Deviation, *White: White immigrants

Cultural Incompatibly in Health and Social Services

Table 2 shows how minority family caregivers experienced cultural incompatibility in health and social services. Participants appeared to have experienced a high level of cultural incompatibility in health and social services (M = 3.72, SD = 1.62; range 0-5). Among five situations of cultural incompatibility in health and social services, the top one experienced by



participants was "The professionals do not understand your culture" (80/102). Two items were tied for the second most common experience: "The professionals there do not speak your language" (78/102) and "The programs are not specialized for people of your national/religious background" (78/102).

Table 2. Cultural Incompatibility in Health and Social Services

	Yes	No	Mean
	n	n	(SD)
The professionals do not understand your culture.	80	22	.78 (1.00)
The professionals there do not speak your	78	24	.76 (1.00)
language.			
The programs are not specialized for people of	78	24	.76 (1.00)
your national/religious background.			
The professional there are not of your	74	28	.73 (1.00)
national/religious background.			
There is no other client/users of your	70	32	69 (1.00)
national/religious background.			
Total cultural incompatibility in health and			3.72 (1.62)
social services			

Health and Social Services Used and Satisfaction with Service

Table 3 indicates the 14 health and social services used and satisfaction with services among minority family caregivers of older adults. The four health and social services most often used by participants were general medical clinic (97/102, 95.1%), in-home medical services (69/102, 67.6%), out-patient specialized clinic (58/102, 56.9%), and senior center: social activities (58/102, 56.9%). On the other hand, the three health and social services least often used by participants were financial information (18/102, 17.6 %), caregiver support group (20/102, 19.6 %), and legal information (21/102, 20.6 %).



Among 14 health and social services, the three most highly satisfactory services were senior center: social activities (87%), caregiver education sessions (79%), and legal information (76%). In addition, the three least satisfactory the services were in-home respite care (26 %), in-home medical services (49%), and general medical clinic (54%).

Table 3. Health and Social Service Use and Satisfaction with the Services

	Socia	olth and ol Service Use	Satisfaction with Health and Social Service		
	Use	Not Use	Satisfied	Unsatisfied	
	n	n	n (%)	n (%)	
Senior center for social/	58	44	51 (87.9)	7 (12.1)	
recreational activities					
Caregiver education sessions	24	78	19 (79.2)	5 (20.8)	
Legal information	21	81	16 (76.2)	5 (23.8)	
Home maker services	37	65	27 (73)	10 (27)	
Counseling service	31	71	21 (67.7)	10 (32.3)	
Respite care-Day center	40	62	26 (65)	14 (35)	
Respite care-Nursing home	28	74	18 (64.3)	10 (35.7)	
Financial information	18	84	11 (61.1)	7 (38.9)	
Transportation	52	50	30 (57.7)	22 (42.3)	
Caregiver support group	20	82	11 (55)	9 (45)	
Outpatient specialized clinics	58	44	32 (55.2)	26 (44.8)	
General medical clinics	97	5	53 (54.6)	44 (45.4)	
In-home medical services	69	33	34 (49.3)	35 (50.7)	
Respite care-in home	42	60	11 (26.2)	31 (73.8)	



Differences among Caregivers Racial and Ethnic Groups in Overall Satisfaction with the Services and Cultural Incompatibility in Health and Social Services

To examine differences between caregivers' racial and ethnic groups and overall satisfaction with the services and cultural incompatibility in health and social services, ANOVA analyses were conducted. For this analysis, four major racial and ethnic groups (Southeast Asian, East Asian, Black, and White) were included. Because the rest of the groups had small sample sizes (e.g. only two participants identified as West Asian), it was a difficult for the researcher to compare the groups equally, so the researcher used only four major racial and ethnic groups for research question 2.

There was no statistically significant association between caregivers' racial and ethnic affiliation and caregivers' overall satisfaction with services at the p < .05 level, F(8, 93) = 1.18, p = .31. Also, there was no statistically significant difference between caregivers' racial and ethnic groups in cultural incompatibility in health and social services as determined by one-way ANOVA (F(8, 93) = 166, p = .11). (No Table)

Correlations between Variables

Table 4 illustrates correlations between study variables. Overall satisfaction with health and social services was significantly and positively associated with caregiver English language proficiency (r = .22, p < .05) and familiarity with the Canadian health and social care system (r = .31, p < .00). This indicates that caregivers with a higher level of English proficiency and a higher level of familiarity with the Canadian health and social care system were more likely to feel higher levels of overall satisfaction with services.

Also, overall satisfaction with health and social services was inversely associated with caregiver burden (r = -.25, p < .05) and cultural incompatibility in health and social services (r = -.23, p < .05). This indicates that caregivers with a higher level of care burden and a higher level



of experience with cultural incompatibility in health and social services were less likely to feel overall satisfaction with services. The remaining variables (caregiver's age, gender, immigration status and French proficiency) were not associated with overall satisfaction with services.



Table 4. Correlations among Study Variables

	1	2	3	4	5	6	7	8	9
1. Caregiver age		10	07	21*	23*	.18	.10	.10	.13
2. Caregiver gender		_	06	02	.02	01	.21*	.06	09
3. English proficiency				.10	06	.23*	21*	12	.22*
4. French proficiency					.17	.12	07	24*	.05
5. Immigration status						.01	04	13	.09
6. Familiarity with the Canadian Health and Social care system						_	07	12	.31**
7. Care burden							_	07	25*
8 Cultural incompatibility in Health and Social Services									23*
9 Overall satisfaction with Health and Social Services									

Note **p*<.05; ***p*<.01



Predictors of Satisfaction with Health and Social Services

Table 5 summarizes the results of the hierarchical regression model of satisfaction with health and social services. In the first model, caregivers' socio-demographic variables accounted for 14 % of the variation in overall satisfaction with health and social services, F(6, 95) = 2.63, p = .02. Only caregivers with a higher level of familiarity with the Canadian health and social care system were significantly more satisfied with overall satisfaction with health and social services, b = 2.62, p = .02, 95% CI [.51, 4.74]. The second model, when care burden was added, explained an additional 4 % of the variance, F(7, 94) = 2.98, p = .00. This indicated that caregivers with a lower level of care burden, b = -.21, p = .04, 95% CI [-.41, -.02] and a higher level of familiarity with the Canadian health and social care system were significantly more satisfied with services, b = 2.53, p = .02, 95% CI [.45, 4.61]. The last model, when cultural incompatibility in health and social services was also included, explained an additional 4 % of the variance, F(8, 93) = 3.34, p = .00. Hence, caregivers with a higher level of cultural incompatibility in health and social services were significantly less satisfied with overall satisfaction with services, b = -.85, p = .03, 95% CI [-1.61,-.09]. Also, caregivers with a lower level of care burden, b = -.24, p = .02, 95% CI [-.44, -.05] and a higher level of familiarity with the Canadian health and social care system were significantly more satisfied with services, b =2.32, p = .03, 95% CI [.27, 4.37] when these variables were included in the final model.



Table 5. Regression Model of Overall Satisfaction with Health and Social Services

Step	Predictor	В	β	t	R^2	Adjusted	ΔR^2
						R^2	
1	Caregiver age	.05	.12	1.18	.14*	.09	.14
	Caregiver gender	97	07	73			
	English proficiency	1.72	.16	1.58			
	French proficiency	.15	.01	.14			
	Immigration status	1.47	.11	1.10			
	Familiarity with the	2.62	.25	2.46*			
	Canadian health and						
	social care system						
2	Caregiver age	.06	.15	1.43	.18**	.12	.04
	Caregiver gender	38	03	28			
	English proficiency	1.32	.12	1.22			
	French proficiency	.11	.01	.11			
	Immigration status	1.45	.11	1.11			
	Familiarity with the	2.53	.24	2.41*			
	Canadian health and						
	social care system						
	Care burden	21	21	-2.12*			
3	Caregiver age	.06	.16	1.61	.22**	.16	.04
	Caregiver gender	13	01	11			
	English proficiency	1.10	.10	1.02			
	French proficiency	34	03	33			
	Immigration status	1.21	.09	.94			
	Familiarity with the	2.32	.22	2.25*			
	Canadian health and						
	social care system						
	Care burden	24	24	-2.44*			
	Cultural	85	22	-2.22*			
	incompatibility						

Note *p<.05; **p<.01; ***p<.001



Discussion

The findings of this study contribute to current understanding of cultural incompatibility in health and social services insofar as increasing satisfaction with services among minority family caregivers of older adult relatives with chronic illnesses in Canada remains an important issue. Minority family caregivers in this study appeared to have experienced a high level of cultural incompatibility in health and social services. The majority of minority caregivers in this study reported being unable to access service in their language of preference, and service providers culturally misunderstood clients' cultures or national/religious background.

A key finding of this investigation is that even after accounting for caregiver burden and other elements of caregiver social location, the relationship between cultural incompatibility in health and social services and overall satisfaction with services remained significant. This finding is consistent with parallel research on discrimination and service satisfaction in marginalized groups (Jang, Kim, & Chiriboga, 2005; López-Cevallos, Harvey, & Warren, 2014; Sorkin et al., 2010). For example, the Jang and colleagues' (2005) study found that older Korean American participants with no experience of discrimination or disrespect in medical settings were more likely to have higher levels of satisfaction with health services. Even though Jang and colleagues' (2005) study did not target minority family caregivers of older adults and was conducted in the United States, the findings indicate that when socially excluded groups, such as older Korean Americans, receive culturally appropriate services, agencies' efforts to help minority caregivers feel satisfied are even more successful. These findings are in keeping with the current study, in which the findings indicate that agencies could better enable clients to care for their loved ones with chronic illnesses by providing appropriate cultural and linguistic services to reduce dissatisfied with service experience on the part of health and social agencies.



Secondly, this study found that there were no significant differences among the caregivers' racial and ethnic minority groups in overall satisfaction with services and in cultural incompatibility in health and social services. This suggests that participating racial and ethnic minority caregivers were vulnerable to the same level of cultural incompatibility in services in the context of Montreal. However, this finding is inconsistent with two studies in parallel literature that examined racial/ethnic discrimination in healthcare and found a significant difference in discrimination in healthcare and satisfaction with service among racially and ethnically diverse groups (Benjamins & Whitman, 2014; Sorkin et al., 2010). One possible explanation of difference between the current study and previous studies is that while these American studies focused on discrimination in healthcare and satisfaction with services among general racial and ethnic groups, the population of the current study focused on Canadian racial and ethnic minority family caregivers of older adult relatives with chronic illnesses. This population is usually at heightened risk in terms of service needs than general racial and ethnic groups. Therefore satisfaction with services by level of cultural incompatibility might not differ among the racial and ethnic groups in the current study compared to previous research.

Third, many studies suggest that lack of English proficiency is a barrier to access agency-based services or might negatively impact satisfaction with services (Bauer et al., 2010; Kang et al., 2010; Ohtani, Suzuki, Takeuchi, & Uchida, 2015); however, this study found that there was no significant relationship between English proficiency and overall satisfaction with services. This lack of association could be the result of a higher level of English proficiency in the current sample. To be specific, caregiver participants in this study had strong English capacity; hence, language was not a barrier, which impacted overall satisfaction for them. The results could also be due to the geographic location of this study. This study took place in



Quebec, where French is the official language. As such, English capacity might not be as important as French capacity in the service locations examined in this study. It should be noted that in places with a lower percentage of proficient English speakers, a lack of translation services would be a much bigger problem, which could be a service barrier in relation to service satisfaction.

Lastly, although it is not one of the main findings of this study, it should be mentioned that while inpatient and outpatient medical services were the service type most frequently used, they were also the services with which minority family caregivers were most frequently dissatisfied. Medical services often function as the entry point to the health and social service system (Maayan, Soares-Weiser, & Lee, 2014). It is possible that negative experiences in this area could result in the delay of services directly targeting caregiver support, such as in-home respite or daycare programs.

Limitations of the Study

Three major limitations should be considered for future studies. First, because this study used a cross-sectional design, it could not draw causal inferences. The second limitation is the generalizability. Specifically, the sample in the current study targeted minority caregivers who immigrated to Canada from non-French and non-English speaking countries or members of ethnic or racialized minority groups and who live in Montreal, Canada. For this particular population, there was no sampling frame, so the researcher recruited participants via snowball and purposive sampling techniques. Thus, the sample might not reflect the population. In addition, the findings of this study might not be generalizable to other minority caregivers of older adult relatives in other cities in Canada.



Lastly, minority family caregiver participants in this study might have been confused about one of the items on the satisfaction with health and social services items. The item asked caregiver participants to rate their satisfaction after accessing health and social services. The phrasing of the question, related to medical services, could have been interpreted to mean either medical services for caregivers or medical services for care recipients. When family caregiver participants in this study filled out the survey, the researcher was with the participants on site; however, none of the participants asked the researcher for clarification on this item.

Nevertheless, the item could be further refined.

Implications for Practice and Research

Despite these limitations, the current study contributes to the caregiving literature, specifically with regard to minority family caregivers in the community. To provide better health and social services, two main points from the study should be addressed in practice and in future research: hiring more staff with diverse ethnic or minority backgrounds and improving the quality of medical services.

First, it is recommended that health and social agencies hire more staff with diverse ethnic or minority backgrounds. Seventy-four percent of participants in this study reported that the health and social service agencies they frequented did not employ providers of their same background. Although family caregivers frequently use medical services, medical professionals, such as doctors and nurses, are often found to lack racial and ethnic diversity when compared to other service providers (Sabin, Marini, & Nosek, 2012). A more diverse staff of medical professionals would better reflect the diversity of the caregivers. If minority caregivers are given the opportunity to receive services from staff who have the same or similar ethnic backgrounds as the clients, the caregivers are likely to feel more satisfied with services than if they work with



staff who are from different ethnic backgrounds (Dong, Chang, Simon, & Wong, 2011; Ngui & Flores, 2006). Therefore, a more diverse staff is required in medical settings, especially in positions that affect the formulation of programs and policies.

Second, it is necessary for service providers and policy makers to think about how to improve the provision of medical services in both in-home and general practice settings. This study found that among the 14 health and social care services, in-home medical services, outpatient specialized clinics, and general medical services were used by the vast majority of minority family caregivers. These services, however, had satisfaction scores centering around 50% indicating a major failure in the system. It is possible that health care settings do not offer culturally appropriate services (e.g. interpreters) to minority clients, or that there are other issues related cultural incompatibility. Long waiting times for an appointment and complication of the medical care process could also negatively affect minority family caregivers in terms of service satisfaction. The findings from the current study highlight that overall medical services still need to be improved for minority family caregivers and their loved ones with chronic illnesses. However, the reasons behind the caregivers' dissatisfaction need further study. Thus, future research is needed to examine the behind reasons why satisfaction scores for medical services are lower among minority family caregivers.

The current policies on aging in North America highly emphasize "Aging in place", which indicates that older people receive various services and care at home instead of in long-term care facilities (Morley, 2012). As such, home-based medical services in particular are an essential part of care for helping minority family caregivers. When care recipients have several chronic illnesses, they might use both institutional services and in-home services. In this situation, when caregivers and their recipients are dissatisfied with both services, they might end



up not using the services at all thus increasing their care burden and general stress level.

However, the improved medical services would enable family caregivers to provide better care for their loved ones at home in the long-term as well as prevent potential issues that relate to caregiving stress. Therefore, policy makers and service providers should be aware of this issue and think about their critical roles in supporting minority family caregivers.

Conclusion

The findings of the current study provide evidence that cultural incompatibility in health and social services is a significant factor when it comes to dissatisfaction with services among minority family caregivers of older adult relatives in Canada. Based on these findings, it is recommended that hiring more staff with diverse ethnic or racial minority backgrounds, as well as examining the reasons behind caregiver's dissatisfaction with medical service provision are needed to assist minority family caregivers in the effort to increase their access to health and social services.



Link between Study 2 and Study 3

Both the second study and the third study focused on how environmental factors (i.e. cultural incompatibility in health and social services and daily discrimination) impact service satisfaction and service use. The second paper entitled "Is It Too Much To Request Fair Services?: Association between Cultural Incompatibility in Health and Social Services and Satisfaction with Services among Minority Family Caregivers" demonstrates how cultural incompatibility impacts satisfaction with health and social services among minority family caregivers. The findings of this study indicated that a higher level of cultural incompatibility in health and social services was associated with a lower level of overall satisfaction with services among minority family caregivers. It is expected that lower levels of satisfaction with services will lower service use and that daily discrimination will also lead to lower service use which is another indicators of service access. Building on this finding, the third study entitled "The Impact of Daily Discrimination on Health and Social Services Use among Minority Family Caregivers" examined daily discrimination (e.g. another environmental factor), which includes all types of discrimination that people experience on a day-to-day basis in utilizing health and social services among minority family caregivers. The aim of this study is to fill a gap in the extant literature by focusing on minority family caregivers of older adult relatives with chronic illnesses. In order to answer the question in this study, the insights from the survey data were primarily drawn upon.



Chapter 4. Ph.D. Dissertation Study 3:

The Impact of Daily Discrimination on Health and Social Services Use among Racial and Ethnic Minority Family Caregivers.

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Abstract

Background: Research on health services has shown that language barriers and cultural preferences for informal support play a role in the low use of agency-based services among racially and ethnically diverse family caregivers. Despite the discrimination that racially and ethnically diverse people experience in daily life, the extent to which discrimination plays a role in the patterns of how family caregivers use health and social services has yet to be explored.

Aim: The aim of this study is to explore the effects of daily discrimination faced by caregivers from minority families on their use of health and social services when caring for older adult relatives.

Research Questions: This study has two research questions to: (1) in what circumstances do minority family caregivers of older adult relatives with chronic illnesses in Canada report facing daily discrimination? and (2) does perceived daily discrimination impact health and social service use among minority family caregivers?

Methods: A cross-sectional survey was conducted with 102 racial and ethnic minority family caregivers of older adults with chronic illnesses in Montreal, Canada. The sample was drawn from communities and religious organizations, informal referrals, social service providers, and on site recruitment by the principal investigator. Daily discrimination (the independent variable) was measured using the Everyday Discrimination Scale (EDS: Williams et al., 1997). Use of health and social services (the dependent variable) was measured by asking the frequency with which participants use specific types of health and social services. Bivariate analysis and hierarchical multiple regression were conducted by using SPSS 24.

Results: Among the 102 participants, the majority of minority family caregivers were female, and immigrants, had a mean age of 60. Caregivers with a higher level of reported discrimination



in daily life tend to use more health and social services. However, this relationship disappeared when controlling for care burden and other variables in the regression model.

Conclusion: Findings of this current study suggest that minority family caregivers perceive discrimination in daily life, which affects their trust in and expectations of health and social service providers. While previous experiences may deter some from accessing services, increased caregiving demand eventually necessitates service use for many. Within this context, it is integral for service providers to respond sensitively to the needs of ethnically and racially diverse caregivers so that previous experiences of discrimination are no replicated.



Introduction

Many older adults who require care for chronic illnesses prefer to stay and receive care in the community rather than live in institutional settings such as long-term care facilities (Allan, Ballard, Rowan, & Kenny, 2009; Chatterji, Byles, Cutler, Seeman, & Verdes, 2015; Perreault, Rousseau, Provencher, Roberts, & Milton, 2012). This preference can place a great demand on family members who provide approximately 80% of all community-based care for older adults (Chatterji et al., 2015; Woodward, 2011). While there are many positive aspects to caregiving, it can also create financial, physical, emotional, and social challenges for family members (Bevans & Sternberg, 2012; Lai, 2012). As such, health and social services, such as in-home care, respite care, and day programs have been developed to support family caregivers in their role and address some of these challenges (Redfood, Feinberg, & Houser, 2013).

Findings from existing literature indicate that health and social services can support older adults' preferences to remain in the community for longer which can mitigate the psychological distress associated with caregiving such as depression and care burden (Hsu et al., 2014; Lee, 2015; Lee & Choi, 2013). While these results are promising, ensuring equitable access to such services is therefore of concern to social workers. Recent work also implies that some pockets of the caregiving population, such as racial and ethnic minority caregivers, reap far fewer benefits from these systems, in part because they are less likely to use them (Scharlach et al., 2006; Woodward, 2011). Impediment to service use identified in the literature suggest that cultural factors such as preferences for informal support or strong beliefs in filial responsibilities may play a role in these patterns (Chow, Auh, Scharlach, Lehning, & Goldstein, 2010; Lee & Choi, 2013). More recently, however, racism, discrimination, language proficiency and lack of cultural sensitivity have also been identified as potentially impacting access for this growing population



of Canadian family caregivers (Chow et al., 2010; Scharlach et al., 2006; Stewart, Neufeld, Harrison, Spitzer, Hughes, & Makwarimba, 2006).

In particular, discrimination based on race and ethnicity is commonly experienced by minority family caregivers in their daily lives and may be influencing their comfort in utilizing agency-based services. Common features of discrimination include disadvantages or harm imposed on people as a consequence of their affiliation with a protected group known to be vulnerable to differential treatment (Young, 2013). Discrimination may have lifelong effects and can vary in form, from individual harassment (e.g. experiencing negative looks or comments or receiving poorer services in shopping centers) to system-related barriers (e.g. getting consistently fewer opportunities at work or education; Pincus, 1996; Utsey, Ponterotto, Reynolds, & Cancelli, 2000). As the Canadian population continues to become more diverse, many people tend to overlook how discrimination experienced by minority family caregivers negatively impacts decisions or opportunities in their daily lives.

Many researchers have indicated that there are varying types of discrimination experiences that may affect individuals or groups differently. In the current study, daily discrimination is defined as negative experiences which minority family caregivers encounter in their daily lives as a consequence of their race/ethnicity and/or immigration status (Canadian Human Rights Commission, n.d; Ontario Human Rights Commission, 2008). People from racial and ethnic minority groups, however, tend to report more of these experiences in daily life than people from dominant racial and ethnic groups (Puhl, Andreyeva, & Brownell, 2008; Young, 2013). For example, in the Brondolo and colleagues (2005) study, based in the U.S, about half of the Black and Latino participants reported at least one ethnically related event [for example "being looked at in a mean way" (57%) or "being ignored" (51%)] at least once in the previous week. Their study



reported that participants were discriminated more frequently in public places compared to other settings (such as in the criminal-justice system and religious institutions).

These findings imply that when racial and ethnic minority family caregivers need services for their caregiving, longstanding and frequent experiences of discrimination may play a role in the decisions of caregivers to delay service use as a form of self-protection (Scharlach et al., 2006; Khan, Kobayashi, Lee, & Vang, 2015). It should be noted that the impact of daily discrimination on service use is not limited to service-related discrimination; rather, daily discrimination refers to all discrimination experienced by participants in their day-to-day life. As a result of current and previous discrimination in daily life, minority family caregivers might predict additional negative experiences in health and social service settings when accessing services for supporting their caregiving. It is possible that based on their previous experience, they might not use needed services or they might limit their use of services. These issues are experienced on top of issues that family caregivers already experience, such as a need to expend extra effort to seek out health or social services due to lack of transportation or family situations preventing accessing services such as needing to take care of their care recipients. In this regard, these combined factors negatively impact the ability of minority family caregivers to use services, as supported by a study on discrimination and health care use (Burgess, Ding, Hargreaves, Van Ryn, & Phelan, 2008). Burgess and colleagues (2008) indicate that perceived discrimination in general could impede an ethnic minority group from accessing dominant culture institutions. Despite the documented reality that racial and ethnic minority group members experience discrimination in daily life, the extent to which discrimination plays a role in the patterns of service use for minority family caregivers has yet to be explored in Canada (Ayalon & Gum, 2011).

Discrimination and Service Use

A handful of studies have investigated the relationship between discrimination and

healthcare use. These studies have commonly found that people who experience discrimination in daily life report more distress and are less likely to use health services (Harris et al., 2012; Rüsch et al., 2009; Priest et al., 2013; Thornicroft, Rose, & Kassam, 2007; Torres, Driscoll, & Voell, 2012; Wahoush, 2009). Despite the contribution of these studies to the body of knowledge on the relationship between discrimination and healthcare use, these previous studies are mostly based on U.S populations. In addition, these previous studies focus on something other than racially and ethnically diverse caregivers and fail to explore service use for both health and social care services typically accessed by family caregivers of older adults (Burgess et al., 2008; Huang, Apple, & Ai, 2011; Spencer, Chen, Gee, Fabian, & Takeuchi, 2010). Taken together, the extent to which these findings extend to patterns of both health and social service use amongst racially and ethnically diverse family caregivers of older adults with chronic illnesses in a Canadian context is as yet unknown. Addressing this critical gap in the caregiving literature, the current study aims to: (1) describe the daily discrimination reported by minority family caregivers of older adult relatives with chronic illnesses in Canada and (2) examine the relationship between perceived daily discrimination and health and social service use among minority family caregivers.

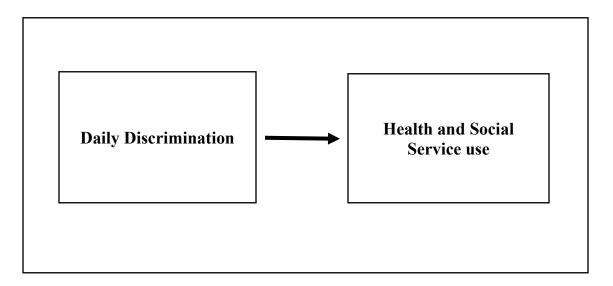
Conceptual Framework

The current study utilizes the Andersen Behavioral Model (1995) as a guiding framework through which to examine minority family caregivers' encounters with daily discrimination and its connection with health and social service use. Andersen's original model (1995) was developed to provide a better understanding of the environmental factors and population characteristics which may support or interfere with health service use. Due to its comprehensive nature, the model has been widely used with a variety of populations - including minority groups (Casado, van Vulpen, Davis, 2011; Hochhausem, Le, & Perry, 2011). While Andersen's



Behavioral Model (1995) suggests that environmental factors such as social policies and norms can be expected to play a role in service use, daily discrimination (which is prevalent in the environment of minority group members) has not been accounted for in studies using this model to explore service use (Phillips, Morrison, Andersen, & Aday, 1998 p. 576). Addressing this gap in the literature, the current study explores the relationship between daily discrimination and service use amongst minority caregivers (See Figure 1).

Figure 1. Conceptual Framework



Research Questions

This study has two research questions to: (1) in what circumstances do minority family caregivers of older adult relatives with chronic illnesses in Canada report facing daily discrimination? and (2) does perceived daily discrimination impact health and social service use among minority family caregivers?



Methods

Design

This study used a cross-sectional survey design to explore the relationship between daily discrimination and health and social service use among minority family caregivers of older adult relatives in Canada.

Sample

The sample for this study included 102 racial and ethnic minority family members of community-residing older adults (65+) living with degenerative physical and cognitive chronic conditions that required ongoing support. Eligible participants: (1) were 21 years or older; (2) had enough language capacity to complete the questionnaires in English or French with some assistance; (3) were either immigrants to Canada from non-French or English speaking countries or members of ethnic or racial minority groups; (4) were primary non-paid caregivers of persons 65+, residing in the community, and requiring assistance with at least two ADLs/IADLs; (5) had used or tried to use health and social services to support their caregiving within the last 12 months; and (6) lived in Montreal.

Data Collection

Purposive and snowball sampling techniques were used to recruit study participants.

First, the primary author approached organizations across the health and social service sector in Montreal inquiring about the possibility of engaging in on-site recruitment at programs used by caregivers including support groups, educational programs and day centers. There organizations were also asked to post the study information in their organization's flyers and newsletters.

Organizations embedded within racially and ethnically diverse communities were also sought to act as sites of recruitment. These targeted samplings methods have been identified as effective



when seeking participation from marginalized groups (Dias, Gama, & Rocha, 2010; Polli, Batey, Bender, Ferguson, & Thompson, 2013).

All potential participants were screened for eligibility by the researcher either by telephone or in person prior to participation. After checking the participant eligibility criteria, the researcher attained informed written consent from participants. The researcher then administrated the study survey. Structured questionnaires were used in data collection and provided in English or French. The one time survey took 25-30 minutes to complete, was available in either French or English and included a series of validated measures and questions that together inquired about experiences of discrimination in daily life, utilization of social and health care services, informal support use, and caregivers' demographic characteristics. During survey administration, those participants who indicated use of less than three types of services were verbally asked to elaborate on the reasons for their level of service use. Their responses were written down in the form of field notes and were used to assist with the interpretations of quantitative findings. The study methods were approved by the McGill University Research Ethnics Board (REB-2 #141-0817).

Measurement

Independent Variable

Daily Discrimination. To assess caregivers' encounters with daily discrimination, the Everyday Discrimination Scale (EDS; Williams, Yu, Jackson, & Anderson, 1997) was utilized. The nine items scale asks participants to report how often they have encountered a series of events ranging from being treated with less respect than others because of their affiliation with a particular group to being insulted, threatened or harassed as a consequence of an affiliation with a protected group. The Everyday Discrimination Scale (EDS) has been utilized to measure



discrimination in health care literature and with various racial and ethnic groups (Lewis, Aiello, Leurgans, Kelly, & Barnes, 2010; Mossakowski, 2003). Each question has six possible responses (0= Never, 1=Less than once a year, 2= Few times a year, 3=A few times a month, 4= At least once a week, and 5= Almost every day) with total possible scores ranging from 0 to 45. Higher total scores indicated more overall experiences of discrimination. Participants reporting discrimination "a few times a year or more" on at least one item are also asked to identify which aspect of their social location they believe to have resulted in the discrimination based on a list of 11 possible protected categories (i.e. gender, race, age, religion, sexual orientation). An 'other' category is available for those who do not identify with any of the listed groups. Hence in addition to capturing discrimination frequency the measure also captures the extent to which discrimination is attributed to race/ethnicity. The reported reliability of the EDS was 0.80 (Taylor, Kamarck, & Shiffman, 2004) which indicates high reliability. Cronbach's alpha for this measure was high in the present sample (α = .805).

Dependent Variable

Use of Health and Social Services. To assess caregivers' use of health and social services, participants were asked to indicate the frequency with which they used specific types of health and social services to support their caregiving within the last 12 months from 0 ("Never") to 5 ("Everyday"). Based on the health and social service programs in the literature and programs and services available for caregivers within the context of the study, a list of 14 health and social services was identified: counseling service, respite care (i.e. day care center, temporary placement, and in-home respite), caregiver support group, caregiver education, transportation (e.g. municipally funded adapted transportation or transportation from a community agency), legal information, financial information, medical services (in-home medical services, general medical clinic, or outpatient specialized clinic), home maker services (e.g. household chores, or

meals), and use of a senior center for social/recreational activities. Health and social services use scores were obtained by summing the frequency with which each listed service was used; scores ranged from 0 to 70. A higher total score indicated that people had a higher frequency of health and social services use. Cronbach's alpha for this measure was moderate in the present sample $(\alpha = .60)$.

In addition, participants who had reported that they used less than three services among the list of 14 health and social services were asked by the principal investigator to describe the reasons for their non-use. Asking participants to verbally discuss non-use rather than reporting on non-use via an open-ended written questions allowed the lead author to probe and explore responses that may have otherwise not been offered (Gallagher & Krawczyk, 2013).

Control Variables

Control variables, including a caregivers' socio-demographic information, care demand, and informal support were collected from minority family caregivers to adjust for other factors that might influence health and social services use. Factors listed have been found to affect use of health and social services in the caregiving or healthcare literatures (Casado et al., 2011; Harris et al., 2012; Toler Woodward, Taylor, & Chatters, 2011).

Caregivers' socio-demographic variables. Caregivers' socio-demographic variables included caregivers' age (years), gender (1 = Male, 2 = Female), immigration status (1 = Yes, I immigrated to Canada permanently, 2 = No, I was born in Canada, 3 = No, I have temporary status in Canada, and 4 = No, I don't have an official status in Canada), and language proficiency (English and French). Language proficiency and immigration status in particular have been consistently identified as bearing an impact on service use (Perreault et al., 2012; Wang & Kwak, 2015).



Care demand. Care demand was assessed by the use of the revised Katz's index of independence in Activities of Daily Living (ADL) (Shelkey, & Wallace, 2002; Katz, Down, Cash, & Grotz, 1970) and of the Lawton Instrumental Activities of Daily Living (IADL: Lawton & Brody, 1969) scale by quantifying the extent to which care recipients required assistance with 13 activities. Recipients requiring assistance with a particular task were scored one and those not requiring assistance were scored zero (possible scores ranging from 0-13). Previous studies on caregiving have found that higher levels of caregiver demand are associated with more service use (Hsu et al., 2014; Mosher et al., 2013). A higher total score indicated that caregivers had a high level of care demand. Cronbach's alpha for this care demand measure was high in the present sample (α=.80).

Informal support. Caregivers' informal support was measured using a modified version of the social support scale from the Resources for Enhancing Alzheimer's Caregivers Health (REACH) II study (Schulz et al., 2003). These 15 items consist of four different domains of informal support: 1) Received Support (three items, by Krause (1995) and Barrera et al. (1981), 2) Social Network (four items, by Lubben (1988), 3) Negative Interaction Subscale, (four items, by Krause (1995), and 4) Satisfaction with Support (four items, by Krause (1995)). Types of responses differed based on each domain of the social support scale. The total score ranged from 0 to 53; a higher score indicated a positive level of informal support. The reported reliability of the social support scale was 0.81 (Rodakowski, Skidmore, Rogers, & Schulz, 2012) which indicates high reliability. Cronbach's alpha for this social support measure was high in the present sample (α = .839).



Data Analyses

A series of univariate, bivariate, and multivariate analyses were conducted for this study. First descriptive statistics were calculated for caregiver socio-demographic variables, informal support, care demand, and health and social services use, to offer a basic understanding of the characteristics of caregivers in the sample. Second, Pearson correlations were conducted to test for associations between all study variables. Lastly, a hierarchical multiple regression was used to examine associations between caregivers' experiences of discrimination in daily life and utilization of health and social services while controlling for other significant variables. This sequential order of entering the variables was based upon typical hierarchical multiple regression guidelines, first entering demographic variables and then entering the second important variables which are more than demographic variables, and then finally entering the main independent variable (Cohen, West, & Aiken, 2014; Petrocelli, 2003). Caregivers' background characteristics were entered in the first block of the regression model. Care demand and informal support variables were added to the regression model's second block. Finally, daily discrimination was included in the regression model's third block. All assumptions were met for hierarchical regression, including no multicollinearity between variables. The level of significance was set at 0.05. All analyses were performed using SPSS statistics program version 24.0.

All verbal reports of reasons for non-use of services were recorded in the form of field notes and analyzed using techniques from summative content analysis in two stages (Hsieh & Shannon, 2005). First, all listed reasons were examined and placed into broader categories (e.g. overall barriers vs service specific barriers). Second frequencies were calculated to paint a picture of the extent to which each category was mentioned by study participants.



Results

Descriptive Information of Sample and Study Variables

Table 1 presents socio-demographic descriptions of caregiver participants and study variables. Among 102 participants, the majority were female, immigrants (n = 84, 82.4%), with a mean age of 60. The fifteen participants born in Canada self-identified as East Asian (n = 3), South Asian (n = 1), Black (n = 3), Southeast Asian (n = 4), Middle Eastern (n = 1), West Asian (n = 1), and Indigenous (n = 2). The combined racial and ethnic identities of Canadian-born and non-Canadian- born participants were East Asian (25.5%), Southeast Asian (20.6%), Black (17.7%), and White (15.7%). The mean score for English proficiency was 2.68 (SD = .57; range 1-3) and for French proficiency was 2.43 (SD = .62; range 1-3). Both of these findings indicate that participants in this study had good communication skills in both English and French. The mean score for care demand was 8.17 (SD = 3.27; range 0-13). This score indicates that caregivers had a medium level of care demand. In addition, participants reported a medium-high level of informal support (M = 34.67, SD = 7.12; range 2-52).



Table 1. Descriptive Characteristics of Sample and Study Variables (N=102)

	Mean (SD)	n (%)
Caregiver age	60.01 (16.51)	
26-59 Years		51 (50.0)
60-69 Years		18 (17.6)
70-79 Years		16 (15.7)
80+ Years		17 (16.7)
Caregiver gender		, ,
Male		31 (30.4)
Female		71 (69.6)
Caregiver immigration status		
I immigrated to Canada permanently.		84 (82.4)
I was born in Canada		15 (14.7)
I have a temporary status in Canada		3 (2.9)
Caregiver race/ethnicity		
White		16 (15.7)
East Asian		26 (25.5)
South Asian		2 (2.0)
Black		18 (17.6)
Southeast Asian		21 (20.6)
Latin American		4 (3.9)
Middle Eastern		11 (10.8)
West Asian		2 (2.0)
Inuit and Others		2 (2.0)
Language proficiency		
English	2.68 (.57)	
French	2.43 (.62)	
Care demand	8.17 (3.27)	
Informal support by family, friends, and	34.67 (7.12)	
others		

Note *SD, Standard Deviation, *White: White immigrants

Caregiver's race/ethnicity was only included for descriptive purposes.



Encounters with Discrimination in Daily Life

Table 2 shows the extent to which minority family caregivers experienced discrimination in their daily lives. Overall, participants reported a medium level of discrimination in daily life (M = 15.5, SD = 3.93; range 12-30). The three situations reported most often by participants were: (1) having people act better than them (M = 2.46, SD = .74); (2) feeling less respected than other people (M = 2.33, SD = .53); and 3) being treated as less smart than other people (M = 2.29, SD = .60). On the other hand, the three situations reported least often by participants were: (1) being threatened or harassed (M = .35, SD = .81); (2) being feared (M = .47, SD = .93); and (3) receiving poorer service at restaurants or stores (M = .90, SD = .101).

Most participants suggested the negative treatment they experienced was a consequence of either their race (51/102, 50%) or their ancestry or national origins (15/102, 14.7%). Hence 66/102 participants (65%) attributed negative treatment to their race and /or ethnicity. Participants also mentioned age (2/102), gender (1/102) and some other aspects of physical appearance (1/102); 32/102 (31%) participants did not respond to this question. This implies that discrimination was largely attributed to race/ethnicity rather than to other elements of social location.



Table 2. Encounters with Discrimination in Daily Life

		Never	Less than once a year	Few times a year	A few times a month	At least once a week	Almost everyday	Mean (SD)
1	People act as if they are better than you are.		<i>J</i>	66	29	3	4	2.46
								(.74)
2	You are treated with less respect than other			70	31	1		2.33
	people are							(.53)
3	People act as if they think you are not smart			78	20	2	2	2.29
								(.60)
4	You are treated with less courtesy than other			74	28			2.27
	people are							(.44)
5	You are called names or insulted.			81	18	2	1	2.24
								(.53)
6	People act as if they think you are dishonest			84	18			2.17
								(.38)
7	You received poorer service than other	47	26	23	5	1		.90
	people at restaurants or stores.							(1.01)
8	People act as if they are afraid of you	75	12	12	1	1	1	.47
								(.93)
9	You are threatened or harassed.	82	9	7	3	1		.35
								(.81)
	Total Discrimination in Daily Life							11.71
								(6.44)



Utilization of Health and Social Services

Table 3 provides an overview of the frequency with which participants used 14 health and social services. Overall, participants appeared to be at a low level of health and social services use (M = 11.72, SD = 6.45; range 0-40). Among these services, the four most used services were general medical clinics (97/102, 95.1 %), in-home medical services (69/102, 67.6 %), outpatient specialized clinics (58/102, 56.9 %), and senior centers for social and recreational activities (58/102, 56.9 %). Alternately, the three least used services were financial information (18/102, 17.6 %), caregiver support groups (20/102, 19.6 %), and legal information (21/102, 20.6 %). This result implies that while overall participants used more medical care services than social care services; they regularly used specific social care services, such as senior centers.

Through the administration of the survey by the principal investigator, 25 participants indicated that they used less than three services among the list of 14 health and social services. Summative content analysis shows that participants reported low use of services for the following reasons: (1) they did not know whom to ask for the information (n = 17); (2) they could not receive educational and informational services from agencies in their own language (n = 8); and (3) they did not have time to assimilate any information received (n = 17).



Table 3. Health and Social Service Uses

	Never	A few times a year	Once or twice a month	About once a week	Several times a week	Everyday	Mean (SD)
General medical clinics	5	57	32	5	3	0	1.45 (.79)
In-home medical services	34	37	22	4	4	1	1.11 (1.10)
Outpatient specialized clinics	44	41	11	3	3	0	.82 (.94)
Senior center for social/recreational activities	44	4	6	19	27	2	1.87 (1.78)
Transportation	50	19	8	12	12	1	1.21 (1.49)
Respite care-in home	60	18	10	6	4	4	.90 (1.38)
Respite care-Day center	62	10	6	8	14	2	1.09 (1.59)
Home maker services	65	7	9	5	6	10	1.11 (1.74)
Counseling services	71	18	7	4	2	0	.50 (.93)
Respite care-Nursing home or residence	74	20	8	0	0	0	.35 (.62)
Caregiver education sessions	78	16	6	2	0	0	.33 (.67)
Legal information	81	20	1	0	0	0	.21 (.43)
Caregiver support group	82	10	7	2	1	0	.33 (.77)
Financial information Total Health and Social Service Use	84	15	3	0	0	0	.20 (.47) 11.72 (6.45)



Correlations between Variables

Table 4 illustrates correlations between study variables. Caregiver gender (r = .20, p < .05), care demand (r = .28, p < .01), and discrimination in daily life (r = .23, p < .05) were statistically and positively associated with health and social service use. These results indicate that female caregivers, caregivers with a higher level of care demand, and caregivers with a higher level of experience with daily discrimination were more likely to use health and social services. Also, caregiver French proficiency (r = -.23, p < .05) was statistically and negatively associated with health and social service use. This indicates that caregivers with a lower level of French proficiency were more likely to use health and social service. The rest of the variables (caregiver age, English proficiency, informal support, and immigration status) did not statistically correlate with health and social service use.



Table 4. Correlations among Study Variables

	1	2	3	4	5	6	7	8	9
1. Caregiver age		10	07	21*	23*	16	.10	06	.14
2. Caregiver gender			06	02	.02	.26**	.13	10	20*
3. English proficiency				.10	06	12	20*	44	.08
4. French proficiency				_	.17	09	.14	.20*	23*
5. Immigration status						.10	01	.01	04
6. Discrimination in daily							.08	23*	.23*
life									
7 Care demand								11	.28**
8 Received informal									19
support by family, friends									
9. Health and Social									
Service Use									

Note * p < .05; **p < .01



Predictors of Health and Social Service Uses

Table 5 summarizes the results of the hierarchical multiple regression model of utilizations of health and social services. The first model which included socio-demographic variables (e.g. caregiver age, gender, immigration status, English, and French proficiency) found that socio-demographic variables contributed significantly to health and social service use, F (5, 96) = 2.59, p = .013, accounting for 12 % of the variation. Specifically, female caregivers, p = 3.02, p = .03, 95% CI [.35, 5.70] and with a lower level of French proficiency, p = -2.16, p = .04, 95% CI [-4.21, -.12] were significantly associated with more health and social service use.

The second model, when caregiving demand and informal support variables were included, explained an additional 10 % of the variance in health and social service use, F(7, 94) = 3.75, p = .001. Specifically, caregivers with a higher level of caregiving demand, b = .62, p = .00, 95% CI [.24, .99] and with a lower level of French proficiency, b = -2.64, p = .01, 95% CI [-4.67, -.61] were significantly associated with more health and social service use. However, in the model 2, caregiver age, gender, English proficiency, immigration status, and informal support were not statistically associated with health and social service use.

After controlling for all of the background characteristics, care burden, and informal support variables, experiences of discrimination were entered as the last model. The model explained an additional 3 % of the variance in health and social service use, F(8, 93) = 3.85, p = .001. However, contrary to the researcher's expectation, the data showed that experiences of discrimination in daily life were not statistically associated with health and social service use, when all other factors were controlled, b = .31, p = .05, 95% CI [.-01, .63]. In the final model, caregivers with a higher level of caregiving demand, b = .61, p = .00, 95% CI [.23, .98], with a higher level of English proficiency, b = 2.25, p = .03, 95% CI [.18, 4.33] and with a lower level



of French proficiency, b = -2.47, p = .02, 95% CI [-4.48, -.46] were significantly associated with more health and social service use.

Table 5. Regression Model of Health and Social Service Uses

Step	Predictor	В	β	t	R^2	Adjusted R ²	ΔR^2
1	Caregiver age	.05	.13	1.33	.12*	.07	.12
	Caregiver gender	3.02	2.2	2.24*			
	English proficiency	1.36	.12	.21			
	French proficiency	-2.16	21	21*			
	Immigration status	.26	.20	.19			
2	Caregiver age	.03	.09	.90	.22**	.16	.10
	Caregiver gender	2.30	.17	1.77			
	English proficiency	2.01	.18	1.91			
	French proficiency	-2.64	25	-2.58*			
	Immigration status	.21	.02	.17			
	Care demand	.62	.31	3.24*			
	Informal support	06	07	75			
3	Caregiver age	.05	.12	1.22	.25**	.18	.03
	Caregiver gender	1.75	.13	1.34			
	English proficiency	2.25	.20	2.16*			
	French Proficiency	-2.47	24	-2.44*			
	Immigration status	.00	.00	.00			
	Care demand	.61	.31	3.21**			
	Informal support	03	03	34			
	Daily discrimination	.31	.19	1.94			

Note N=102; *p < .05; **p < .01; ***p<.001

Discussion

The current study sheds new light on the importance of understanding the experiences of daily discrimination faced by racial and ethnic minority family caregivers when utilizing health and social services in Canada. Three major conclusions can be drawn from this study.



First, while caregivers in this study appeared to experience at a medium level of daily discrimination, they reported more frequent exposure to subtle forms of discrimination such as being treated with less respect than others or being treated as less intelligent. Caregivers in this study frequently attributed this treatment to their racial or ethnic affiliation. This result is supported by a study which examined the health status of immigrants in Canada (De Maio & Kemp, 2010). In their study, the authors found that minority and immigrant participants who experienced discrimination or experienced unfair treatment were most likely to experience a decline in self-reported health status. De Maio and Kemp (2010) indicated that experiences of discrimination led immigrants to stop receiving services in Canada, which negatively impacted their health status. Findings from previous studies and the current study imply that service providers supporting minority family caregivers can expect that many will have had past negative experiences because of their race/ethnicity, which, if replicated during service provision, could exacerbate distress and result in cessation of needed services.

Second, contrary to the principal investigator's hypothesis and the previous findings in literature that includes the use of mental health services (Burgess et al., 2008; Chae, Lee, Lincoln, & Ihara, 2012), this study found that caregivers with a higher level of reported discrimination in daily life were significantly associated with using more rather than less health and social services in a bivariate analysis. However, the relationship between discrimination and service use disappeared when controlling for caregiver demand and other variables in a multivariate analysis. Possible explanations for the rejection of the hypothesis have to do with the focus of previous, related literature (Burgess et al., 2008; Richman, Kohn-Wood, & Williams, 2007; Spencer et al., 2010; Trivedi & Ayanian, 2006). The previous literature focused on populations and types of service use that were different in comparison to those examined in



the current study. Whereas previous studies used American participants and focused solely on mental health services, this study uses Canadian participants and includes both health and social services. The differences between these populations could account for the differences in results. To clarify this issues, it is recommended that more studies focus on Canadian populations and multiple types of service use.

These findings suggest that once family caregivers experience a certain level of care demand, they may have no choice but to utilize services despite past experiences with discrimination. Hence, while family caregivers with low demand who have histories of discrimination may utilize the strategy of delayed use to protect themselves from further harm, this strategy is no longer available once demand is such that caregivers must access services.

Once again this conclusion speaks to the need for service providers to consider the possible impact of previous experiences with daily discrimination on the use of health and social services. For example, while minority family caregivers may have little choice but to access medical or tangible services to support their caregiving roles, they may elect to opt out of services designed to provide them with emotional support such as support groups and educational programs fearing a repetition of past experiences with exclusion and alienation. In fact, findings of the current study show that caregiver specific programs (e.g. counseling services, caregiver education sessions, and caregiver support group) were used less often than medical services by caregivers.

Previous studies on caregiving have shown that educational and support programs help minority family caregivers not only to prevent care burden but also to provide better care for their loved ones with chronic illnesses living in the community (Hafsteinsdóttir, Vergunst, Lindeman, & Schuurmans, 2011; Washington, Meadows, Elliott, & Koopman, 2011). Therefore, efforts should be made by service providers to help ease the care burden of minority family



caregivers, which involves acknowledging daily experiences of discrimination in order to avoid negative associations with use of services. One way of approaching this problem is to work collaboratively with ethnically and racially diverse communities to develop more inclusive support services for minority family caregivers. For example, the findings of the current study show that minority family caregiver participants frequently used senior centers, which suggests that these spaces could offer inclusive support services for them.

Lastly, this study found that caregivers with lower levels of French proficiency were more likely to use health and social services. This finding was also unexpected given that French capacity is more commonly associated with improved access to services in the province of Quebec where French is the predominant language of service provision. This finding is inconsistent with a previous study in other contexts which examined English proficiency and mental health service use among Latino and Asian immigrants and indicated a lack of English skills as a significant barrier to the use of agency-based services (Kim et al., 2011). There are two possible explanations for the findings of this study. First, caregivers in the current study used services despite language proficiency simply because they required the help. Second, caregivers were able to access a large number of services in English. However, participants in the current study were not asked about specific information regarding service agencies that they used (e.g. providing services in English, French, or both). Therefore, future research should examine this aspect to come to a more comprehensive understanding about the relationship between language proficiency and service use among minority family caregivers.

Limitations of the Study

Even though the findings of the current study contribute to the caregiving literatures, there are several limitations that arise from the interpretation of the findings. First, this current



study utilized cross-sectional design, which cannot draw causal inference. A longitudinal design would be helpful to better examine the relationships between caregivers' experiences of discrimination in daily life and utilization of health and social services. Second, because the sample in the study was drawn from only one city in Canada, the findings of the study cannot be generalized to the rest of Canada. Minority family caregivers' experiences of health and social service use and discrimination in daily life in Montreal may differ from other cities in Canada. Future study should gather data from various regions in Canada. Third, the study focused only on minority family caregiver participants who used health and social care services, hence the opportunity to capture delayed use or non-use was limited. Future research should recruit caregivers currently supporting older relatives regardless of service use. In doing so, this would allow for an exploration of the extent to which discrimination affects non or delayed service use. On a related note, the survey questions in the study did not include items regarding when family caregivers knew of care recipients' chronic symptoms and when family caregivers actively started looking for health and social services. These items might be helpful for future researchers and service providers to understand the relationship between service needs and service use. Lastly, the discrimination scale used in this study may not have fully captured the extent to which this population experienced daily discrimination. For example, some of the items on the scale may not have been ideal for an older adult caregiver population. One of the items was "You received poorer service than other people at restaurants or stores." This item presumes outings to restaurants and stores, which may not reflect the daily patterns of older caregiver participants (Nicholson, 2012). As such, the item was infrequently endorsed by participants. Therefore, a more developed discrimination scale should be used for future research and should be validated with the population.



Conclusion

Many racially and ethnically diverse caregivers have experiences of discrimination in daily life, which affects their trust in and expectations of health and social service providers.

While previous experiences may deter some from accessing services, increased caregiving demand eventually necessitates service use for many. Within this context, it is integral for service providers to respond sensitively to the needs of ethnically and racially diverse caregivers so that previous experiences of discrimination are no replicated.



Chapter 5. Conclusion

Key Findings Across the Three Studies in the Context of Previous Research

The overall aim of this dissertation is to enhance the understanding of access to the Canadian health and social service system by racial and ethnic minority family caregivers of older adults with chronic illnesses. The first paper examined fourteen health and social services and investigated whether or not they were perceived to have met the needs of minority family caregivers. The first paper also examined how population characteristics and an environmental factor affect unmet needs in health and social services among minority family caregivers. The second and third papers investigated how environmental factors such as cultural incompatibility and daily discrimination impact service satisfaction and service use, respectively, among minority family caregivers.

The first study found that fewer care recipient medical issues resulted in greater levels of unmet caregiver needs— a finding with mixed support in the literature (Black et al., 2013; Hoogendijk et al., 2014; Li, Kyrouac, McManus, Cranston, & Hughes, 2012). There are a number of possible interpretations for these results. It is possible that given the way community services are allocated (based on care recipient function versus caregiver need) caregivers whose relatives have fewer physical limitations are offered fewer services despite the demands they may still be experiencing in caring for their relatives. Care recipient function may be a poor indicator of caregiver need as some caregivers experience stress and burden even when their relatives have few demands for daily assistance. In light of these discrepancies, caregiving advocates suggest that service provision should be allocated through assessment of caregiver need alongside care recipient function (Shin et al., 2011). The C.A.R.E. Tool is an example of a standardized assessment tool that could help to identify when service allocation based on



caregiver need is warranted (Fancey, Keefe, Guberman, Barylak, & MacLeod, 2008). By using an assessment tool to improve service allocation, identifying and responding to these unmet service needs can improve minority family caregivers' access to the specific services they need rather than all services in general.

In the first study, the highest unmet needs were found to be in the area of professional services (i.e. caregiver support groups, providing financial and legal information, and counseling services). These findings are consistent with previous research (Black et al., 2013; Lam et al., 2011; Washington et al., 2011). Cultural incompatibility between clients and service providers, and low usage of ethno-culturally specific services both were also associated with a higher level of unmet service needs. These results correspond with similar literature that highlights the importance of culturally sensitive services, which reduce unmet service needs (Boneham et al., 1997; Koehn & Badger, 2015). Aside from suggestions on how to directly address each of these concerns, it may be helpful to consider how they may impact each other. It may be that a part of the reason that there is such a high level of unmet needs in the areas of financial and legal information provision, counseling services, and caregiver support is that these services are not being offered in a culturally-sensitive manner. This goes beyond language (which is an important part of cultural compatibility and ethnic specific service provision). To reduce cultural incompatibility, it may be advisable to tailor these professional services to the particular cultures, which service providers are trying to reach. Modified services based on cultural needs might result in more service access and increased specialized assistance for family caregivers (Griner & Smith, 2006). Cultural incompatibility was also found to be an important environmental factor in the area of service satisfaction (Study 2) as a higher level of cultural incompatibility was found to be connected to a lower level of service satisfaction among minority family caregivers. This



association between cultural incompatibility in health and social services and service satisfaction corresponds with the relationship found in parallel research on discrimination and service satisfaction in marginalized groups (Jang et al., 2005; Sorkin et al., 2010). This finding is important because a minority family caregiver's level of satisfaction with health and social services is not just a matter of feeling discomfort, cultural incompatibility in this area can make minority family caregivers feel isolated and increase their care burden (Ahmed et al., 2016; Dias, Gama, & Rocha, 2010). Dissatisfaction with services can lead to a reduction of service use, leaving caregivers with a reluctance to use needed services and an increase in unmet service needs (Casado, van Vulpen, & Davis, 2011; Ngui & Flores, 2006).

Although the finding regarding the significant relationship between cultural incompatibility and lower service satisfaction was in concurrence with the literature, the fact that this relationship was present for all caregivers regardless of their affiliation with specific minority or ethnic groups (indicating that minority caregivers all suffered from similar levels of inequity in services) contradicts parallel research in discrimination in which particular racial and ethnic groups were impacted more than others (Benjamins & Whitman, 2014; Sorkin et al., 2010). This contradiction may be due to the current state of the Canadian health and service care system rather than any differences between how various racial and ethnic minority groups react to experiencing cultural incompatibility. If this is the case, it seems critical for policy makers and service agencies to reconsider how to provide culturally-sensitive services to family caregivers in order to reduce cultural incompatibility and increase service satisfaction.

The final paper in this dissertation examined the relationship between another environmental factor and access to health and social services. Specifically, this final paper investigated how perceived discrimination in daily life impacted health and social service use.



Findings from this paper revealed that minority caregivers reported being treated with less respect and less intelligence as a consequence of their racial/ ethnic affiliation. However, contrary to the researcher's expectation and findings from other research (Burgess et al., 2008; Chae, Lee, Lincon, & Ihara, 2012; Spencer et al., 2010), daily discrimination was not significantly associated with service use when examined alongside other factors. It is possible that minority family caregivers in this study were forced to use services despite their exposure to daily discrimination. This would be logical with regards to critical or urgent services (such as medical services). With these services, caregivers and care recipients would be forced to ignore any discomfort they might feel from environmental factors such as daily discrimination. It is also possible that these results might in part explain the high unmet needs in professional services identified in the first study (such as caregiver support groups and legal information) as those services may have been viewed as more optional than immediate services such as medical care. In this case, it is possible that the discomfort caused by daily discrimination may dissuade caregivers from using these less urgent services while the more immediately needed services remain in use. This possibility would need to be explored in further studies, however, as it is not possible to determine if this is true given the research in this dissertation.

Strengths and Limitations for Future Research

Strengths

The first strength from this dissertation is that this dissertation represents one of the first attempts to examine how environmental factors (e.g. cultural incompatibility in health and social services, and daily discrimination) affect access to health and social services among minority family caregivers of older adult relatives. Some researchers in the U.S (Spencer et al., 2010; Woodward, 2011) have examined the relationships between health service use and discrimination generally; however, relatively little research considers the addition of social



service component, cultural incompatibility, and daily discriminations. By doing so, findings from this dissertation provide salient evidence that minority family caregivers experience cultural incompatibility in health and social services and daily discrimination while accessing health and social services for supporting their caregiving.

Second, the three articles it contains shed light on examining access to health and social services: unmet service needs, satisfaction with services, and services use among racial and ethnic minority family caregivers. This is the first paper which combines these three concepts under the umbrella of access to social services. This connection can help researchers better conceptualize the links between these distinct areas of research which this dissertation. The visualization of relation between these concepts is offered in the version of the Andersen Behavioral Model for Access to Health and Behavior Services specially revised for this dissertation. By examining each of the access to health and social service indicators (i.e. unmet service needs, satisfaction with services, and service use), findings from the three articles of this dissertation work to close important gaps in the caregiving literature.

Lastly, by using quantitative methods, this dissertation focuses on a vulnerable population: minority family caregivers who take care of their older relatives with chronic illnesses. Generally, issues of minority family caregivers are not frequently examined in the caregiving literature. Of the research that has been conducted with this population, the majority has been done in North America and the researchers have primarily utilized qualitative methodology. To add to this research pool, the current dissertation study conducted its study in Canada, and has utilized quantitative research methods. Despite the challenges associated with recruitment of ethnically and racially diverse persons in research, this study included the



experiences of 102 minority caregivers-a substantial sample size for a hard to research population.

Limitations

This dissertation has several major limitations that should be considered when interpreting the findings. Related directions for future research are also proposed. First, sampling bias might be a problem in this dissertation. A nonprobability self-selection sampling strategy (i.e. convenience sampling and snowball sampling) was utilized to recruit racially and ethnically diverse minority family members of community-residing older adults (65+) with chronic illnesses. Due to sampling bias, the findings of this dissertation study might not be generalizable to other minority caregivers of older adult relatives in different cities in Canada. The inability to calculate response rate may also lead to a type of sampling bias called nonresponse bias. This can affect results if the people who chose not to participate were intrinsically different to the current participants. To reduce the sampling bias, future research should collect the samples across different cities and health and social service agencies in Canada.

Second, this dissertation used a cross-sectional design, which limits the researcher's ability to test causal relationships between variables. Future research may endeavor to collect longitudinal data to explore casual relationships between discrimination and the use of health and social services by minority family caregivers.

Third, this dissertation had measurement issues with the included discrimination scale and some scales which were developed and used to examine access to health and social services by the researcher. In the third study, the researcher used the validated Everyday Discrimination Scale (EDS; Williams et al., 1997) to examine daily discrimination; however, some of items in the scale were not enough to capture the daily discrimination among minority family caregivers. For example, one of items was "you received poorer service than other people at restaurants or



stores." While administrating the survey, the researcher came to realize that the study population (e.g. older adults and family caregivers) may not have had enough time or have had a chance to go to restaurants due to several reasons (e.g. financial concerns, caregiving duties). For future research, it is recommended that researchers further develop scales for measuring discrimination which can provide more comprehensive coverage and relevance for an older population of caregivers.

To examine access to health and social services, two of the dependent variables used (i.e. service use and unmet service needs) were measured with items developed by the researcher. This was done as no other appropriate measures are available in the research literature to capture these concepts as needed for this dissertation. These measures have not been fully examined for reliability and validity. The scales were in the form of checklist-style questions with either dichotomous answers (Yes or No) or frequency answers (Never, A few times a year, Once or Twice a month, About once a week, Several times a week, and Everyday). Thus, the internal consistency (e.g. Cronbach's alpha) for these scales to measure access to health and social services was unable to be calculated. In addition, to test the face validity of the scales, the principal investigator consulted with social workers and professors who had worked with family caregivers of older adults before using this measure in the survey. After receiving their assessment, the researcher incorporated the feedback into the revised instrument. However, other tests for validity must still be conducted. Therefore, it would be a helpful for future researchers to further develop these scales to improve validity and reliability.

Implications for Social Work Policy, Practice, and Research

The key findings of this dissertation provide meaningful implications for social work policy and practice. As mentioned in Study 1, minority family caregivers reported a higher level



of unmet needs in the areas of caregiver support groups, financial and legal information, counseling services, and caregiver educational services. This finding implies two things: 1) minority family caregivers need more direct caregiving resources and 2) service agencies and policy makers need to think where and how to deliver these kinds of services. First, to fulfill unmet needs and reduce the impact of daily discrimination, policy makers and service providers should consider offering caregiving services in locations which may be more comfortably accessed by the intended population - in senior centers, for example. One of the findings from this dissertation study is that except for medical services, minority family caregivers frequently used senior centers for social/recreational activities (see Study 2). Therefore, senior centers could be used as ideal places to offer the services for minority family caregivers. Offering professional services, such as support groups and the provision of financial and legal information, in senior centers may improve access for minority family caregivers by ensuring that these unmet needs are provided outside of traditional service locations. Another option could be to hold a free community service day for minority family caregivers. On particular dates, various caregiving services could be set up in a public location in the community where minority family caregivers could visit and partake in the professional services available for supporting their caregiving. Caregivers who have a positive impression of the services may then be more likely to use the services more in the future either at the traditional service agency location or at communitybased locations (e.g. senior centers). This should in turn reduce unmet service needs and reduce the impact of cultural incompatibility on service access.

The findings of this dissertation show that caregivers' experiences of cultural incompatibility in health and social services (see Studies 1 and 2), caregivers' lack of ethnic-specific service use (see Study 1), and limited connection to a religious community (see Study 1)



may negatively affect access to health and social services among minority family caregivers of older adults – specifically in the areas of unmet service needs and dissatisfaction with services. To provide more effective services, policy makers and service agencies might consider collaborating with community experts. Having more staff who are familiar with and sensitive to different racial and ethnic groups, and who are familiar with their clients' cultural values should be beneficial for minority family caregivers. This is because providing better representation for ethnically and racialized service providers may be a step towards demonstrating inclusivity. However, due to the limited budget that many service agencies are limited to for hiring staff, requesting the addition of more diverse personnel might not be a realistic solution to fill this gap. One way to fill the gap may be through collaboration with community experts - for example, with religious leaders and community advocators. Through working with community experts, service agencies can develop practical guidelines to provide better services for racial and ethnic minority family caregivers (Nora et al., 1994). Part of the mission statement for one of the CIUSSS subsystems in Montreal is to strive to provide services tailored to their users' language and ethnic background (Mission and values, n.d) whenever possible. Following this mission, it may behoove policy makers to make a requirement for culturally based training (either provided by the community experts or developed with their assistance) regularly and then to evaluate the results based on reasonable criteria. It is thought that providing training to service providers may result in better quality of services for minority family caregivers. This may also benefit the community experts, as they might feel more included by being allowed to share not only their concerns for themselves and for minority family caregivers with service agencies but also contribute their knowledge for the benefit of their community. With all parties contributing to the

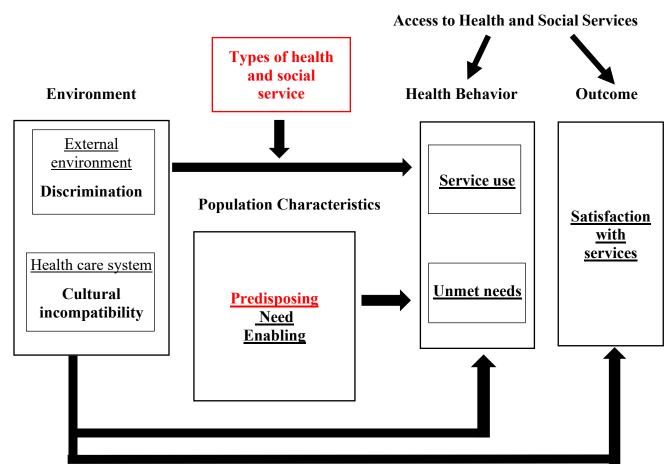


problem, minority family caregivers might not only use health and social services more, but they may also be more satisfied with the services when they need help and resources.

Implications for Theoretical Frameworks

To examine the experiences of racial and ethnic minority family caregivers in terms of access to the Canadian health and social service system, all three papers of this dissertation used one theoretical framework: Andersen's Behavioral Model of Health Service Use (1995). Overall, there were clear areas of application for this theoretical framework in the current dissertation study; however, some parts in the model should be explored more to further understand access to health and social services among minority family caregivers (Figure 4).

Figure 4. Reproposed Framework to Investigate Access to Health and Social Services





Environmental Factors

External environment. The external environmental factor, which is a part of the larger environment category in the model, was considered to be daily discrimination for this dissertation. Specifically, the third paper of this dissertation examined whether daily discrimination as an environmental factor impacted service use among minority family caregivers; however, based on the results it was concluded that a further examination of the relationship between daily discrimination and service use in the Andersen model is required with the inclusion of a possible moderating variable. Unlike Andersen's original model (which shows that there is an indirect relationship between environmental factors and health behavior), the third paper in this dissertation anticipated a direct relationship between the environmental factor (i.e. daily discrimination) and the health behavior (i.e. service use). Contrary to the researcher's expectation, this current study found no direct relationship between these when controlling for other variables. It is possible that there is a moderating variable (for example, type of health and social service) impacting the relationship between daily discrimination and service use. This supposition was made based on the prominence of a particular type of service used most often by minority family caregivers in this study. In this dissertation, the majority of minority family caregiver participants reported that 'medical services' was the most frequent type of social service used. The popularity of this service type may be due to medical services being the type of service most urgently needed to support their caregiving. Based on these results, it is hypothesized that although daily discrimination may impact service use for less urgently needed services, use of the most urgently needed services (e.g. medical services) is not as likely to be affected by daily discrimination. Therefore, to have clear understanding of the relationship



between these variables, it is recommended that future researchers to examine the inclusion of a moderating variable in the revised Andersen model.

Health care system. The health care system, which is another part of the larger environmental category in the Andersen model, was represented by cultural incompatibility in the revised model for this dissertation as this study directly examines how cultural incompatibility in the environment of the healthcare system may affect minority family caregivers. Existing literature regarding the Andersen model has not included the concept of cultural incompatibility as the health care system factor in the environmental category despite the cogency of the logic behind its inclusion. To fill this gap, this dissertation examined the impact of cultural incompatibility on access to health and social services in the areas of unmet needs (Study 1) and satisfaction with services (Study 2) among minority family caregivers. Cultural incompatibility was found to be significantly impact both unmet needs and satisfaction with services in a sample of 102 minority family caregivers of older adults. It is recommended that future researchers consider the inclusion of cultural incompatibility as the health care system factor of the environmental category when using the Andersen Model in research with minority family caregivers.

Population Characteristics

Based on the Andersen model (1995), the population characteristics category includes three factors: predisposing, needs, and enabling factors. The first paper of this dissertation examined which population characteristics were associated with unmet needs; however, the findings of this dissertation shows that more research is needed to test whether the concept of predisposing factors is ideal for inclusion in the revised version of the Andersen Model.

Following this literature, the first study in this dissertation included unmet needs in the health



behavior category to examine how population characteristics (i.e. predisposing, need, and enabling) and an environmental factor (i.e. cultural incompatibility) are associated with a health behavior (i.e. unmet needs). The variables identified as predisposing factors in Andersen's model (i.e. caregiver gender and age) proved not to be associated with the examined health behavior - although according to Andersen's model, they should be. This dissertation study found the need and the enabling factors to be the most important factors regarding their impact on unmet service needs. The definitions of each of the terms lend credence to this finding. Need factors show an indicator of need for a given health and/or social service while enabling factors protect family caregivers from unmet needs when engaging with health and social services and so are integral to the model. Predisposing factors, however, indicate characteristics of the service user and therefore do not automatically lend themselves to impacting service access. For example, when considering age (one of the predisposing factors in this study), it is likely not a participant's age itself which impacts a caregiver's access to services. It is more likely related need or enabling factors (e.g. transportation, or caregiver's medical issues) which affect service access.

Despite this rational and the findings of the current study, some literature on unmet needs (using the Andersen model) have found that predisposing variables are associated with unmet needs. With these mixed findings, it is recommended that future researchers retest the concept of predisposing factors to determine whether the predisposing factors are qualified for inclusion in the population characteristic category, or if modifications in the relationships between factors in the Andersen model might better reflect the links between the factors.

Access to Health and Social Services

Health behaviors and Outcome. As indicators of access to health and social services, both health behaviors (i.e. unmet needs and service use) and outcome (i.e. satisfaction with



services) were utilized for this dissertation. Although not originally conceptualized as a health behavior factor by Andersen, unmet needs has been included in the health behavior category by other researchers in the literature on service use. The results of this study indicate that the relationship between the majority of the population characteristics and the health behavior unmet needs performed as predicted; thus indicating a good fit for this model. Additionally, in the revised model, the category heading of access to health and social services was added with connections illustrated between this topic and both the health behavior and outcome factors. This addition to the model illustrates the links between each of the indicators of service access which were discussed in this dissertation. These connections, although useful for conceptualizing the links between the included factors, were not tested in this study. Future researchers who are considering further investigation into access to health and social services using the Andersen model might consider testing the addition of this component hypothesized to provide added clarity of the links between factors.

The search for access to services and the quest for equality in services is imperative for the health and well-being of racially and ethnically diverse minority family caregivers. The receipt of these services can help caregivers reduce their care burden and better equip themselves to care for their loved ones with chronic illnesses. This dissertation is a stepping stone for future research in this area and provides a foundation for how policy makers and service providers can more fully serve minority family caregivers.



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Chapter 1 (Introduction)

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Chapter 3 (Ph. D Dissertation Study 2)

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Chapter 5 (Conclusion)

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Appendix A: Consent form

Research Participation Consent Form-McGill University School of Social Work

Research Title: The Impact of Experiences of Discrimination on Social and Health Care Service Use and Satisfaction among Racial and Ethnic Minority Family Caregivers of Older Adult Relatives in Canada.

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H4A 2H2

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Supervisor Contact Information: Email: tamara.sussman@mcgill.ca

You are being invited to participate in a doctoral study entitled "The Impact of Experiences of Discrimination on Social and Health Care Service Use and Satisfaction among Racial and Ethnic Minority Family Caregivers of Older Adult Relatives in Canada" which is being conducted by Eunyoung Lee, Doctoral Candidate at McGill University's School of Social Work. The purpose of this study is to learn how minority family caregivers who have either immigrated to Canada or who identify as being a part of a visible minority group use and experience social and health care services.

What is required of participants: If you agree to participate in this study, you will be asked to fill out one survey that asks about your use of and experience with social and health care services. The survey also asks about experiences with discrimination and some demographic questions. The survey takes approximately 20-30 minutes to complete. The survey can be completed in English or in French. If you are not comfortable reading or writing in English or French the Principal Investigator may be able to locate someone who can translate the questions and help you to answer them. The survey can be completed at a location of your choice and the principal investigator (and a translator if necessary) will be available to help you complete the survey. Participating in this study is completely voluntary. You can skip any questions or withdraw from the study at any time. What are the risks and benefits of participation: Thinking about caregiving experiences can sometimes be emotional. The principal investigator, who is a trained social worker, will be available to field any of your questions or concerns as you complete the survey and will be sensitive to your reactions. Your participation is voluntary and will have no impact on the services provided to you and your loved one. Your responses or decision to participate will not be shared with any of the organizations you receive services from and you may stop participating at any time- by skipping a question or returning the survey. While there are no direct benefits to participants, the findings from this study will suggest recommendation that will improve satisfaction with social and health care services for family caregivers of older adult relatives. How will my confidentiality be preserved: All participants in the study will be assigned an identification code and only the principal investigator (Eunyoung Lee) and her supervisor (Tamara Sussman) will know the code. This code will be kept on the principal investigator's



password protected computer. If a translator is needed to fill out the survey for a participant, the

translator will be asked to respect the confidentiality of the interview. However in this case both the researcher and the translator will be aware of the individual responses of respondents. After the data is collected only the principal investigator and her supervisor will have access to it. To be specific, all raw hard copy data (printed survey materials) will be stored in the locked cabinets in either the PhD student Social Work office, Wilson Hall room 313, McGill University campus, or on the principal investigator's password protected computers in the office. All data (printed survey materials) will be entered using the identification code with identifying information removed. All data that is reported will be aggregated and no individual results will be reported. In the final report, only aggregate data will be presented. Any publications that may result from this study will respect the confidentiality of the participants. At no time will either names or specifics about the facility that could be used for identification be included in any reports, summaries, published articles, or presentations. Your signature serves as your agreement to participate in the study; however, you have the opportunity to withdraw your participation at any time.

Who can be contacted to discuss the study: If you have any questions or concerns about your participation in the study please contact Eunyoung Lee (514) 398-7055 or via email at Eunyoung.lee@mail.mcgill.ca or her supervisor Dr. Tamara Sussman at (514) 398-2265 or via email at tamara.sussman@mcgill.ca. If you have any concerns or questions about your rights or welfare as a participant in this research study, please contact the McGill Ethics Officer Deanna Collin at (514) 398-6193 or via email at deanna.collin@mcgill.ca. REB number is 141-0817

Consent

I have read and fully understand the purpose of this dissertation research and the risks and benefits it presents to me as stated above. I agree to participate in this study. I have been given a signed copy of this consent document for my records.

Participant's signature	
Participant's printed name _	
Survey Date:	



Appendix B: Survey

Dear Caregiver,

My name is Eunyoung Lee and am a social work doctoral candidate at McGill University. I am conducting my doctoral thesis on how racial and ethnic minority family caregivers experience and use social and health care services to support their caregiving. The survey takes between 20-30minutes to complete. This survey is completely voluntary. Your choice of participation (or your refusal) will not affect the services you receive in any way. Your individual answers will remain confidential and will not be shared with any of the organizations you get support from. I will be available to help you complete the survey. If at any time, there is a question you cannot or do not want to answer please skip it. Please be sure to complete the consent form (attached) before responding to this survey as it provides you with more details about the study. If you have any questions now or later, you are encouraged to contact me, Eunyoung Lee, in person or at the School of Social Work, at McGill University, or by phone: 514-398-7055, or email:

Eunyoung.lee@mail.mcgill.ca.

THANK YOU IN ADVANCE FOR YOUR PARTICIPATION



Demographic Questionnaire

This first set of questions asks you a bit of information about yourself and the person you are caring for including your ages, the length of time you have been caregiving, your racial and ethnic backgrounds, and so on.

	Yourself	Your loved one
How old are you?	Age (in years)	Age (in years)
What is your gender?	Male Female Transgender	Male Female Transgender
Which category best describes your racial/ethnic identity?	White Chinese South Asian Black Filipino Latin American Southeast Asian Arab West Asian Japanese Korean North American Indian Inuit Metis Other(specify)	White Chinese South Asian Black Filipino Latin American Southeast Asian Arab West Asian Japanese Korean North American Indian Inuit Metis Other(specify)
What is your level of education?	Less than high school High school Professional/Vocational degree Bachelor's degree Graduate degree	Less than high school High school Professional/Vocational degree Bachelor's degree Graduate degree
Do you understand English?	No, Not at allYes, I understand a littleYes, I understand it well	No, Not at allYes, I understand a littleYes, I understand it well
Do you speak English?	No, Not at allYes, I speak a littleYes, I speak it well	No, Not at allYes, I speak a littleYes, I speak it well



	Yourself	Your loved one
Do you understand French?	No, Not at all Yes, I understand a little Yes, I understand it well	No, Not at allYes, I understand a littleYes, I understand it well
Do you speak French?	No, Not at all	No, Not at all
	Yes, I speak a little	Yes, I speak a little
	Yes, I speak it well	Yes, I speak it well
Have you ever used ethnic- specific social and health care services?	Yes No	Yes No
Are you an immigrant?	Yes, I immigrated to Canada permanently.	Yes, I immigrated to Canada permanently.
	No, I was born in Canada	No, I was born in Canada
	No, I have a temporary status in Canada	No, I have a temporary status in Canada
	No, I don't have an official status in Canada	No, I don't have an official status in Canada
How many years have you resided in Canada?	Years	Years
Are you familiar with the	Not at all	Not at all
Canadian Social and Health	A little bit	A little bit
Care system?	Very much	Very much
Do you have a car?	Yes No	Yes No
How would you describe your current financial situations?	StrugglingComfortableAffluent	StrugglingComfortableAffluent



	Yourself	
What is your relationship to your care recipient?	SpouseDaughterSonDaughter-in-lawSon -in-lawRelativesOthers	
How long have you been taking care of your loved one?	(Years) (Months)	
Overall, how would you rate your health?	Poor Fair, Good, Very good Excellent	
What is your religion?	No religionChristianBuddhistHinduJewishMuslimAny other religion	
How often do you usually attend religious services?	Never Less than once a year A few times a year A few times a month At least once a week Nearly every day	
Are you currently working?	Yes, Full-time Yes, Part-time No.	



The following questions ask you a bit more information about the type of assistance your relative needs including their medical condition and their functional limitations. Care recipient ADL/IDAL

Does your loved one have difficulty with this activity? Please check yes or no.

	Activities of daily living (ADL)/ Instrumental activities of daily living (IADL)	YES	NO
1	Bathing		
2	Dressing		
3	Toileting		
4	Getting in/out of bed		
5	Continence(Walking)		
6	Feeding(Eating)		
7	Shopping		
8	Cooking		
9	Managing medications		
10	Doing housework		
11	Doing laundry		
12	Managing money		
13	Using the phone		

Please indicate the primary medical condition(s) for which your loved one requires support.

		Yes	No
1	Cancer		
2	Chronic heart problems(i.e. high blood pressure, congestive heart failure)		
3	Chronic obstructive pulmonary disease(COPD) OR Lung disease		
4	Diabetes		
5	Kidney problems		
6	Arthritis, Osteoporosis, or Rheumatism		
7	Partial or complete paralysis		
8	Visual or hearing impairment		
9	Diagnosed depression or anxiety		
10	Parkinson's disease		
11	Dementia		
12	Other		



Impact of Caregiving

Caregiving can place a lot of different demands on family members. The following questions ask you to indicate how, if at all, your caregiving has impacted you. Please indicate the response that best describes how caregiving has affected you for each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1	My life satisfaction has suffered because of the care.				
2	I often feel physically exhausted.				
3	From time to time, I wish I could "run away" from the situation I am in.				
4	Sometimes, I don't really feel like "myself" s before.				
5	Since I have been a caregiver my financial situation has decreased.				
6	My health is affected by the care situation.				
7	Caregiving takes a lot of my own strength.				
8	I feel torn between the demands of my environment (such as family) and the demands of the care.				
9	I am worried about my future because of the care I give.				
10	My relationships with other family members, relatives, friends, and acquaintances are suffering as a result of the care.				



SOCIAL SUPPORT

Some caregivers have a large support system (e.g. friends and family) to rely on to help with their caregiving and others do not. The following questions ask you about the support available to you to help you with your caregiving. Please check the appropriate response as it applies to you.

1. Overall, how satisfied have you been in the past month with the help you have received from family members, friends, or neighbors?

Not at all	A Little	Moderately	Very

2. How many relatives, friends, neighbors, other than care recipient, do you see or hear from at least once a month?

None	One	Two	Three or Four	Five to Eight	Nine or More

3. How many relatives, friends, neighbors, other than care recipient, do you feel close to? That is, how many do you feel at ease with, can talk to about private matters, or can call on for help?

None	One	Two	Three or Four	Five to Eight	Nine or More

4. How many relatives, friends, neighbors, other than care recipient, do you feel you can call on for help with chores, transportation, etc.?

None	One	Two	Three or Four	Five to Eight	Nine or More

5. When other people you know have an important decision to make, do they talk to you about it?

None	One	Two	Three or Four	Five to Eight	Nine or More

6. In the <u>past month</u>, how often has someone, such as a family member, friend, or neighbor, other than care recipient, provided transportation, pitched in to help you do something that needed to get done, like household chores, or yardwork, and/or helped you with shopping?

Never	Once a While	Fairly often	Very often



7. Overall, how satisfied have you been in the past month with the help you have received with transportation, housework and yardwork, and shopping?

Not at all	A Little	Moderately	Very

8. In the past month, how often has someone been there with you (physically) in a stressful situation, provided comfort to you, or expressed concern about your well-being?

Never	Once a while	Fairly often	Very often

9. In the past month, how satisfied have you been with the support, comfort, interest and concern you have received from others?

Not at all	A Little	Moderately	Very

10. In the past month, how often has someone given you information and guidance on some action? For example, they made a difficult situation clearer and easier to understand or told you what they did in a similar situation?

Never	Once a while	Fairly often	Very often

11. Overall, how satisfied in the past month have you been with the suggestions, clarifications, and sharing of similar experiences you have received from others?

Not at all	A Little	Moderately	Very

12. In the past month, how often have friends, neighbors, or family members made too many demands on you?

Never	Once a while	Fairly often	Very often

13. In the past month, how often have friends, neighbors, or family members been critical of you?

Never	Once a while	Fairly often	Very often

14. In the past month, how often have friends, neighbors, or family members pried into your affairs?

Never	Once a while	Fairly often	Very often



15. In the past month, how often have friends, neighbors, or family members taken advantage of you?

Never	Once a while	Fairly often	Very often

16. Do you agree or disagree with the following statement: "I would help within my means if a relative told me that she/he is in financial difficulty"

Strongly disagree	Disagree	Neutral	Agree	Strongly agree

17. Do you agree or disagree with the following statement: "when someone has problems she/he can count on help from his/her relatives"

Strongly disagree	Disagree	Neutral	Agree	Strongly agree

18. Do you agree or disagree with the following statement: "much of what a son or daughter does should be done to please the parents"

Strongly disagree	Disagree	Neutral	Agree	Strongly agree



The following list includes a series of health and social care services that caregivers sometimes use to support their caregiving. For all of the following please indicate the services you needed in the past 12 months, the services you used, the frequency with which you used the services, and your overall level of satisfaction with services.

	have you need	following services led in the past 12 onths?	Which of the following services have you used in the past 12 months?		
	Need	Not Need	Yes	No	
Counseling services					
Respite care-Day center					
Respite care- Nursing home or residence					
Respite care-In home					
Caregiver support group					
Caregiver education sessions					
Transportation for doctor visits,					
shopping or other purposes					
Legal information					
Financial information					
In home medical services (visiting nurse/doctor,					
home health aid, etc.).					
General medical clinics					
(Family doctor, clinic nurse, etc.)					
Outpatient specialized clinics (memory clinic,					
geriatric services, fall center, etc.)					
Home maker services					
(house hold chores, meals)					
Senior center for social/recreational activities					



	How often in the past 12 months have you used each of these services?					Overall, how satisfied were you with each of the services used?			
	Never	A few times a year	Once or twice a month	About once a week	Several times a week	Every day	Satisfied	Unsatisfied	Not applicable
Counseling services									
Respite care-Day center									
Respite care-Nursing home or residence									
Respite care-In home									
Caregiver support group									
Caregiver education Sessions									
Transportation for doctor visits,									
shopping or other purposes									
Legal information									
Financial information									
In home medical services									
(Visiting nurse/doctor, home									
health aid, etc).									
General medical clinics									
Outpatient specialized clinics									
Home maker services									
(house hold chores, meals)									
Senior center for social/recreational activities									



BARRIERS TO SERVICES

The following list includes obstacles that can sometimes get in the way of caregivers getting the services they need. Please indicate from the list below which, if any, obstacle may have interfered with you seeking or receiving services for your caregiving.

		Yes	No
1	Do not know about existing social and health care services.		
2	Do not believe that the professionals can help.		
3	Uncomfortable with asking for help.		
4	Feeling ashamed.		
5	There is no other client/users of your national/religious background.		
6	The professionals are too young.		
7	You worry that you are being seen as having problems.		
8	The professional there are not of your national/religious background.		
9	The professionals do not understand your culture.		
10	The professionals there do not speak your language.		
11	The programs are not specialized for people of your national/religious background.		
12	The office hours are inconvenient.		
13	The waiting list is too long.		
14	The procedures of using the services are complicated.		
15	You do not have the transportation to go.		
16	No one (families or friends) is available to take you there.		
17	The weather is too cold/hot for you to get out		
18	Bad experience heard from others.		
19	The professionals are too busy.		
20	The services are too expense. (Cannot afford to pay)		
21	Not satisfied with the services.		



Overall Service Satisfaction

The following questions ask you a bit more about your overall level of satisfaction with the combination of services you have been using for your caregiving.

		Strongly agree	Agree	Undecided	Disagree	Strongly disagree
1	Things have gotten better since I've been going to social and health care service agencies.					
2	Since I've been using social and health care service agencies, my life is more messed up than ever.					
3	Social and health care service agencies are always available when I need it.					
4	I got from social and health care service agencies exactly what I wanted.					
5	The service providers love to talk but won't really do anything for me.					
6	Sometimes I just tell the service providers what I think they wants to hear.					
7	The service providers are usually in a hurry when I see them					
8	No one should have any trouble getting some help from social and health care service agencies.					
9	The service providers sometimes say things I don't understand.					
10	The service providers are always explaining things carefully.					



Discrimination is a reality that some Canadians face which can impact their daily lives. The following questions ask you to identify, which, if any, circumstances of discrimination you have faced.

		Never	Less than once a year	Few times a year	A few times a month	At least once a week	Almost everyday
1	You are treated with less courtesy						
	than other people are.						
2	You are treated with less respect						
	than other people are.						
3	You receive poorer service than						
	other people at restaurants or						
	stores.						
4	People act as if they think you are						
	not smart.						
5	People act as if they are afraid of						
	you.						
6	People act as if they think you are						
	dishonest.						
7	People act as if they are better than						
	you are.						
8	You are called names or insulted.						
9	You are threatened or harassed.						

10. What do you think is the main reason for these experiences?

- 1. Your ancestry or national origins
- 2. Your gender
- 3. Your race
- 4. Your age
- 5. Your religion
- 6. Your height
- 7. Your weight
- 8. Some other aspect of your physical appearance
- 9. Your sexual orientation
- 10. Your education or income level
- 11. Other_____

Thank you for taking your time to complete this survey!



Appendix C: Flyer

Caregiver Research Racial and Ethnic Minority Family Caregivers of Older Adult Relatives Wanted!

My name is Eunyoung Lee, and I am a doctoral candidate at McGill University's School of Social Work. I am currently looking for family caregivers of older adult relatives to participate in my dissertation study to discuss your social and health care service use and experiences (e.g. sensitivity to cultural needs, discrimination) while caring for your loved ones. Participation involves completing a survey which will take 20-30 minutes. I will be available to help you complete the survey, which may be completed in either English or French. I may be able to provide a translator if you are uncomfortable completing the survey in either of these languages.

If you are:

- 21 years or older
- Caring for a family member who is 65 or older with chronic illnesses at home.
- Either an immigrant to Canada or a member of an ethnic or racialized visible minority group



For participation in this study or more information, please contact the researcher, Eunyoung Lee, MSW, PhD(c) Eunyoung lee@mail.mcgill.ca

I look forward to meeting with you.

This study has been approved by McGill University Research Ethics Board, Study #141-0817. Your individual answers will remain confidential.

Thank you for your help!



