Primary care case management of culturally diverse dementia patients and caregivers, a pilot cross-sectional study in a Montreal Family Medicine Group

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Dedication

For Mom and Dad.

Abstract

Background: Pending the arrival of definitive treatment for dementia — an increasingly common neurodegenerative illness, clinicians look to better utilize available resources to improve patients' and their informal caregivers' quality of life. Case management is an innovative model of care and has been implemented in Quebec in select primary care clinics called Family Medicine Groups (FMG). Often nurses or social workers (also called "infirmiers-pivot" in French), case managers assess and follow dementia patients, coordinating their care and collaborating closely with other members of the healthcare team. However, little evidence exists on how this model of dementia care navigates culturally sensitive contexts, especially given the rich and diverse cultural landscape of Quebec and Montreal.

Objectives: To determine the ethnocultural diversity of dementia patients and their informal caregivers of the Herzl Family Practice Centre, a FMG using case management; to determine whether Canadian born and foreign born service users had different needs and problems.

Methods: 15 community-dwelling dementia patients and their 15 informal caregivers were recruited. We report descriptive statistics of their sociodemographic, ethnocultural, memory and health characteristics, in addition to (a) patient needs using the Camberwell Assessment of Need for Elderly (CANE) and (b) caregiver problems and needs using the Carers' Needs Assessment for Dementia (CNA-D). Dementia severity was measured using the Mini-Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA). We describe differences between Canadian born and foreign born study participants (hypothesis generating).

Results: The 15 patients were on average 76.5 years old (sd: 9.2, range: 61-91), of which 10 were men, still in the early stages of cognitive decline with a mean MoCA of 22.7 (3.4, 15-27). Patients reported "memory", "physical health", "money/budgeting" as common needs, and received both informal and formal help to meet most needs. The 15 caregivers were aged 72.3 years old (12.5, 41-90), with 12 women. They reported "physical or psychiatric illness" and "lack of information about dementia", "about treatment" and "about services" as common problems. They received adequate "diagnosis or treatment" from the family physician, but their needs for "support from a social worker", "printed information material" and other services were not met.

Compared to their 5 Canadian born counterparts, the 10 foreign born patients had more needs (and different needs) and a lower quality of life. This may be explained by their older age, longer onset of memory symptoms, worse cognition and more behavioral symptoms. The 9 foreign born caregivers were younger than their 6 Canadian born peers, but reported more stress associated with their patient's behavioral symptoms, more problems (and different problems) and more needs (and different needs) for services.

Conclusion: These findings may be clinically impactful in the care of our patient population, albeit statistically insignificant due to the small sample size. Valuable insight was gained about the conduct of research with this vulnerable population. The role that cultural diversity can play in the complex environment of dementia case management merits further investigation, in order to better serve all members of a population already vulnerable by age and disease.

Keywords: dementia, culture, ethnicity, needs, case management.

Résumé

Contexte: En attendant l'arrivée de traitement définitif pour la démence — une maladie neurodégénérative de plus en plus commune, les cliniciens cherchent à améliorer l'utilisation des ressources en santé pour augmenter la qualité de vies des patients et de leurs proches aidants. La gestion de cas est un modèle de soin innovatif et a été adoptée dans certains Groupes de Médecine Familiale (GMF). Les gestionnaires de cas sont souvent des infirmiers ou des travailleurs sociaux (aussi appelés infirmiers-pivot) qui évaluent et suivent l'évolution des patients atteints de démence, organisant leurs soins et services et collaborant étroitement avec les autres professionnels de la santé. Cependant, peu d'études se porte sur comment ce modèle de soins pour la démence navigue un contexte qui exige du tact et de la sensibilité culturels, surtout lorsqu'on considère le paysage richement culturel du Québec et de Montréal.

Objectifs: Déterminer la diversité ethnoculturelle des patients atteints de démence et de leurs proches aidants du Centre de médecine familiale Herzl, un GMF utilisant la gestion de cas; déterminer si les usagers de services nés au Canada et nés ailleurs ont des besoins et problèmes différents.

Méthodes: 15 patients atteints de la démence vivant dans la communauté et leurs 15 proches aidants ont été recrutés. À l'aide de statistiques descriptives, nous examinons leurs caractéristiques sociodémographiques et ethnoculturels, ainsi que la sévérité de leur démence et leur santé en général. De plus, nous décrivons (a) les besoins des patients à l'aide du Camberwell Assessment of Need for Elderly (CANE) et (b) les problèmes et besoins des proches aidants à l'aide du Carers' Needs Assessment for Dementia (CNA-D). La sévérité de la démence a été évaluée à l'aide de l'examen de Folstein sur l'état mental (MMSE) et de l'échelle Montreal Cognitive Assessment (MoCA). Nous décrivons les différences entre les participants nés au Canada et nés ailleurs (génération d'hypothèses).

Résultats: Les 15 patients étaient âgés, en moyenne, 76.5 ans (déviation standard : 9.2, intervalle : 61-91). 10 patients étaient des hommes. Les patients étaient dans les débuts de leur déclin cognitif, avec un MoCA moyen de 22.7 (3.4, 15-27). Les besoins des patients les plus souvent déclarés étaient la mémoire, la santé physique et l'argent ou le budget. Les patients ont reçu de l'aide informelle et du soutien professionnel pour satisfaire la presque totalité de leurs besoins. Les 15 proches aidants étaient âgés, en moyenne, 72.3 ans (12.5. 41-90), dont 12 femmes. Leurs problèmes les plus prévalents étaient la maladie physique ou psychiatrique et un manque d'information sur la démence, sur le traitement et sur les services. Ils ont reçu les soins nécessaires de la part de leurs médecins de famille, mais leurs besoins pour le soutien d'un travailleur social, leurs besoins pour des pamphlets ou des livrets d'information et leurs besoins pour d'autre services pertinents n'ont pas été satisfaits.

Comparativement à leurs 10 homologues nés au Canada, les 5 patients nés ailleurs avaient plus de besoins (et des besoins différents) et une qualité de vie moindre. Ces différences ont pu être dues à leur âge plus avancé, une apparition de symptômes relatives à la mémoire plus précoce, des capacités cognitives plus réduites et plus de symptômes comportementaux psychologiques. Les 9 proches aidants nés ailleurs que le Canada étaient plus jeunes que leurs 6 pairs Canadiens, mais ont déclaré un niveau de stress plus élevé associé aux symptômes comportementaux de leurs patients, ainsi que plus de problèmes (et des problèmes différents) et plus de besoins pour des services différents.

Conclusion: Ces résultats pourraient avoir un impact du point de vue clinique dans le soin de nos patients malgré le fait qu'ils ne sont pas statistiquement significatifs à cause de la petite taille de l'échantillon. On a tiré de cette étude des leçons précieuses sur comment mieux travailler auprès de cette population vulnérable. Le rôle que pourrait jouer la diversité culturelle dans cet environnement complexe qu'est la gestion de cas en démence mérite d'être mieux compris à travers des recherches plus approfondies, afin de mieux soigner et servir tous les membres de cette population déjà vulnérable à cause de leur âge et maladie.

Mot-clés : démence, culture, ethnicité, besoins, gestion de cas.

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List of Abbreviations

CANE: Camberwell Assessment of Need for the Elderly

CNA-D: Carers' Needs Assessment for Dementia

MCI: Mild cognitive impairment

MMSE: Mini-Mental State Examination

MoCA: Montreal Cognitive Assessment

NPI: Neuropsychiatric Inventory

QOL-AD: Quality of Life in Alzheimer’s Disease scale

SD: Standard deviation

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Preface

The format of the thesis is traditional.

Contribution of Authors

The present thesis work can be considered as part of two larger initiatives.

Firstly, the broader research context is a multisite, mixed methods study across 6 Family Medicine Groups in Montreal on dementia patients and caregivers needs and use of healthcare resources, led by the thesis supervisors Dr. Vladimir Khanassov and Dr. Isabelle Vedel. This project operates under the Canadian Consortium on Neurodegeneration in Aging (CCNA), supported by the Canadian Institutes of Health Research (CIHR) through the CIHR Dementia Research Strategy. The project is also supported by FRQS and Réseau-1. The present thesis, a pilot cross-sectional study, focused on one of the 6 sites of the larger study. It is one of many Family Medicine Groups that adopted case management for its dementia patient population following the Alzheimer Plan: the Herzl Family Practice Centre, Jewish General Hospital, located in the borough of Côte-des-Neiges–Notre-Dame-de-Grâce in Montreal.

Secondly, the present thesis also serves as the quantitative phase of a pilot mixed methods study led by master's student Xin Qiang Yang at the same study site.

Though the present thesis is embedded within an even larger multisite study led by Yang's thesis supervisors, it is on his suggestion that the cultural dimension of dementia case management in primary care was studied. He introduced and committed to this novel idea based both on a knowledge gap he identified in the existing literature and on the pertinence he believed the topic to have in the local context and practices. For the Herzl site, Yang conducted the great majority of fieldwork and all of the analysis. He led recruitment, visited patients and caregivers and conducted data collection, assisted for a few patients by a research assistant he mentored. He performed the analysis of results independently. (In addition, he collected and analyzed complementary qualitative data as part of the aforementioned pilot mixed methods study, but this was beyond the scope of his thesis.)

Chapter 1: Introduction and General Objective

a. Introduction

i. The growing burden of dementia

Dementia, also more recently known as major neurocognitive disorder [1], is a set of neurodegenerative diseases characterized by progressive cognitive decline affecting daily activities, causing important and increasing mortality and morbidity. The projected growth of its prevalence and associated societal burden over the coming years is impressive, in Canada [2, 3] and worldwide alike [4]. However, beyond the figures and statistics, it is important to remember the condition's direct and intimidating implications for the individual person and their loved ones.

ii. Dementia and the role of primary care

Pending the arrival of definitive treatment for dementia, clinicians, administrators and policymakers look for avenues to optimize existing health services and their delivery, in order to improve the patient's and their informal caregiver's quality of life. Indeed, faced with the rise of dementia, the health apparatuses of many countries have been criticized for the provision of care that is not person-centered, that is fragmented [5]. To provide person-centered and efficient care, it is often necessary to restructure the healthcare services and streamline their delivery.

In the Canadian province of Quebec, the Alzheimer Plan, a ministerial action plan for Alzheimer's disease and related disorders, was devised in 2009, and the future of dementia care was to be based in primary care [6, 7]. Canadawide consensus conferences had been recommending the family physician to become the main resource in detecting and managing dementia, as the family physician is best placed to follow chronic conditions [8]. In some countries elsewhere in the world, similar emphasis was being placed on primary care as the prime, sustainable solution to the increasing burden of dementia [9].

However, existing primary care was not equipped to meet the challenge without adaption, for instance, in performing timely diagnosis and providing expert care [10]. While primary care can be considered prime real estate, further development was needed to achieve its full potential in delivering quality, person-centered and efficient dementia care.

iii. Bringing case management into the picture

In the years following the Alzheimer Plan, primary care in Quebec had been undergoing changes at all levels [6, 7]. Family physicians were to be responsible for the diagnosis and treatment of dementia [6, 7]. In supporting them, select Family Medicine Groups (a healthcare institution that is analogous to a Family Health Team in Ontario or a Medical Home in the United States) had adopted a care model known as case management, utilizing the case manager's expertise to provide continuous, comprehensive and person-centered care and support [6, 7]. Indeed, the Family Medicine Group is a "group of doctors who work closely with nurses in an environment that is conducive to the practice of family medicine" [11], itself a model of organizing and delivering primary healthcare services with a strong emphasis on interdisciplinary collaboration [12, 13]. The addition of a case manager to the Family Medicine Group, then, was a natural extension of this principle to leverage a professional's particular set of skills and expertise in responding to the special challenges of dementia care.

The Case Management Society of America formally defines case management as "a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality, cost-effective outcomes" [14, 15]. In practice, in the reality of clinical care, a case manager is often a nurse or a social worker (often called "infirmier-pivot" in French in the Quebec Alzheimer Plan). They usually perform an initial assessment of the patient complaining of memory symptoms, collaborating closely with the family physician. Then, a care plan is drawn in conjunction with the patient and their informal caregiver, detailing current needs, options for intervention from allied health professionals and community resources. The case manager will continue following the patient and their caregiver longitudinally, responding to their evolving clinical situation and other needs and coordinate care with the appropriate parties. Crucially, a case manager empowers the patient and their caregiver and engages them in decision making. A case manager, then, adopts a person-centered approach in assessing and following the patient and the caregiver, organizing and adapting their care in concert with the family physician and other members of the healthcare team.

iv. Dementia, culture and the cultural diversity of our local context

Though there is favorable evidence for the use of the care model of case management, little research has been conducted on how the model navigates culturally sensitive situations. Disease is a biological disturbance, but its effects reach beyond the patient's body; an individual's personal experience of this event is known as illness, while the even broader social implications of the phenomenon is called sickness [16]. This is of special concern in dementia, a life changing disease that assaults the patient's mind; the ways they or their loved ones perceive and experience these changes are inevitably couched within their culture and worldview, which may differ from or be at odds with those of the health professional. Moreover, the public's understanding of dementia is a dynamic, evolving process influenced by the individual's cultural past [17]. Organizing and delivering effective and efficient dementia care is already complex, which becomes even more so when faced with patients and families of diverse cultural origins [18].

Before proceeding further, it would be essential to offer some definitions. Culture is "a collective expression for all behavior patterns acquired and socially transmitted through symbols. Culture includes customs, traditions, and language" [19].

Then, "a group of people with a common cultural heritage that sets them apart from others in a variety of social relationships" is an ethnic group, an ethnocultural group or an ethnicity [20].

To a limited extent, we engaged in ethnology, a "comparative and theoretical study of culture" [21], meaning how persons' varied accumulated "customs, traditions and language" change their journey of dementia through primary care case management from ethnicity to ethnicity.

The local context in Montreal in which this study took place is particularly diverse in its cultural constituents. According to 2016 Census conducted by Statistics Canada, the population of Montreal was 4,098,927 [22]. Of these, 910,605 (22.22%) spoke another language than English or French (a non-official language) as their mother tongue, and 494,525 (12.06%) spoke a non-official language most often at home [22]. There were 936,305 (22.84%) immigrants, and 70,860 non-permanent residents (1.73%) [22]. Of the immigrants, 210,770 (22.51%) emigrated from the Americas, 254,860 (27.22%) from Europe, 204,635 (21.86%) from Africa, 264,955 (28.30%) from Asia and 1,095 (0.12%) from Oceania and other places of birth [22]. In Montreal, 904,840 inhabitants (22.07%) were visible minorities [22]. However, immigration and physical appearance alone cannot illustrate the ethnocultural richness of Montreal fully. In Montreal, 117,850 (2.88%) reported being of North American Aboriginal origins, 1,861,930 (45.42%) of other North

American origins, 1,721,335 (41.99%) of European origins, 184,035 (4.49%) of Caribbean origins, 135,405 (3.30%) of Latin, Central and South American origins, 321,450 (7.84%) of African origins, 508,290 (12.40%) of Asian origins and 2,450 (0.06%) of Oceania origins [22]. The census also detailed more than 250 finer categories of ethnic origins to which a person may belong [22]. A person could report more than one ethnic origin in the census [22].

The borough where our study site is located is among the most ethnoculturally diverse in Canada. Indeed, the Herzl Family Practice Centre is a Family Medicine Group serving the community of Côte-des-Neiges–Notre-Dame-de-Grâce. In 2016, the borough was home to a population of 166,520, and was the most densely populated borough in Montreal. Among the inhabitants were 76,215 immigrants (45.77%) and 10,405 non-permanent residents (6.25%) [23]. The leading countries of birth by number of immigrants were the Philippines, Morocco, China and France [23]. 76,290 (45.81%) self-identified as visible minorities, 66,175 (39.74%) spoke a non-official language as their mother tongue and 40,455 (24.29%) spoke a non-official language most often at home [23].

b. General Objective

With dementia being particularly demanding in the quality and nuances of its care, with the local population being so ethnoculturally diverse, existing research is lacking in determining whether the concerns of all members of this population already vulnerable due to age and disease are being answered. Given the context of recent reforms in care organization and delivery, one of which was the adoption of case management in Family Medicine Groups, it is especially important to verify if the problems and needs of a culturally diverse patient population, as well as their informal caregivers, are being addressed in this complex care environment.

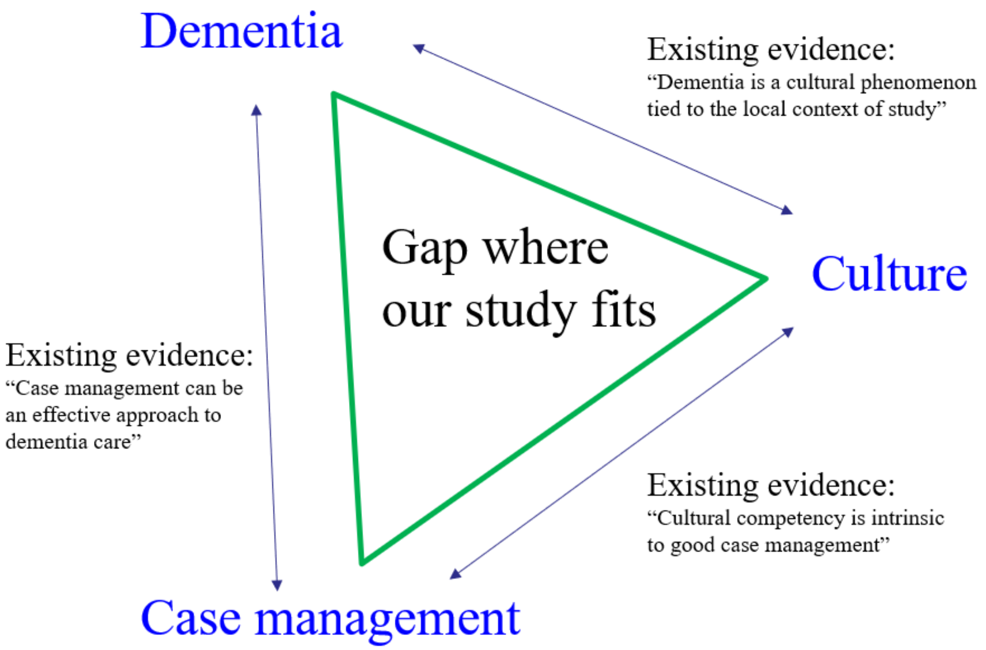
Our purpose, then, is to provide a first insight into primary care dementia case management of patients and their informal caregivers of different ethnocultural backgrounds, in order to identify, protect and better serve potentially marginalized groups within a vulnerable, and growing population of persons affected by dementia.

Chapter 2: Literature Review, Knowledge Gap, Specific Objectives and Research Questions

a. Literature Review

Essentially, our study was to be built on three elements of interest: dementia, case management and culture. In the literature, there was no report of evidence encompassing all three of them at once; a recent systematic review on dementia and case management revealed no articles that addressed culture or ethnicity in relation to care in depth [24]. Indeed, past studies had examined subsets of these three ideas, but were insufficient in addressing the need for evidence in our context of cultural diversity and dementia care. The present review does not aim to systematically report all relevant literature, but rather aims to describe broadly the types of research done in the past, with examples, and to illustrate a knowledge gap to be filled (Figure 1).

Figure 1. Conceptualization of the knowledge gap



i. On dementia and case management: case management can be an effective approach in caring for dementia

Two broad categories of literature on dementia case management are of interest.

In the first category, researchers determined the **impact of case management in dementia care** by examining a variety of outcomes, especially patient and caregiver needs. Quantitative studies also measured other outcomes such as patient and caregiver clinical outcomes, satisfaction, service use and cost-effectiveness. In addition, researchers had explored patient and caregiver needs in dementia case management using qualitative methods. Results of primary care case management of dementia have been inconsistent, though recent literature depicts a promising future [24-26]. In a recent systematic mixed methods review on such needs, researchers conducted a narrative synthesis of 54 studies of various methodologies, developing a classification of patient and caregiver needs and describing the effects of case management on these needs [24]. In the same review, a meta-analysis demonstrated that in case management, patients reported a significant decrease in behavioral symptoms, perhaps because more timely and appropriate pharmacological and non-pharmacological options were adopted compared to usual care [24]. The caregiver's confidence in providing care grew, with potential benefits in alleviating caregiver depression and overall burden [24]. More broadly, the review found that all identified patient and caregiver needs, especially patient education, could be addressed through case management [24].

In the second category, researchers investigated the **implementation of case management in the context of caring for dementia**, particularly in primary healthcare. Qualitative studies reported barriers and facilitators to successfully implementing the case management model of care.

Systematic reviews have been mixing the first and second categories of evidence, mainly to understand how successful and less successful implementation of the case management model of care may account for inconsistencies in its outcomes [25, 26].

In short, dementia case management has been studied extensively, with past literature demonstrating that it requires tact in its implementation, but if done right, it can impact the care of dementia patients and their caregivers positively. However, no study of case management of dementia, whether quantitative, qualitative or mixed, was found to address culture with sufficient depth [24].

ii. On dementia and culture: dementia is a cultural phenomenon tied to the local context of study

Different ethnic groups are affected by dementia differently

There are plentiful scientific publications detailing the differences between dementia patients and caregivers of different ethnic groups [27].

Genetic differences between ethnicities have been investigated, though alone, they cannot fully explain or account for the differences in dementia rates of different ethnic groups [27]. Indeed, the epidemiology of the disease, including the cultural diversity of dementia patients or between-group disparities have been studied and reported considerably [27, 28]. Certainly, **dementia prevalence** and age of onset may differ significantly between two ethnic groups living in the same country and served by the same healthcare system [27, 28]. For example, in the United Kingdom, more African-Caribbean older people developed dementia compared to their United Kingdom born White counterparts and at a younger age, even when adjusted for socioeconomic status [29]. In the Netherlands, dementia was 3 to 4 times more prevalent in non-Western immigrants than the native Dutch population [30]. There are many more such studies, comparing different ethnic groups in different regions of the world.

A dominant portion of the literature features articles detailing how a particular ethnic group of persons affected by dementia, both patients and caregivers, **experience the disease differently** than their peers [27, 31]. Both quantitative and qualitative methods have been used to investigate these differences. Though studies have been conducted across the globe, American studies form a significant portion of the literature on this topic.

A particularly well studied group is the Asian minorities in the United States. For instance, deeply rooted values, particular filial piety, determined Chinese American dementia patients and caregivers attitudes towards stress, coping strategies and support, research and formal help seeking; as a result, they may not receive the care and services they need and deserve [32]. Vietnamese Americans valued filial piety similarly [33]. Asian Americans in general were found to assume caregiving responsibilities at a greater rate than other ethnicities, and may be less likely to call upon formal services to assist them [34]. Chinese Americans held varied and colorful perceptions and understandings of dementia, a lack of knowledge which sometimes lead to stigmatization [35]. Indeed, misconception towards dementia (including stigmatization and normalization) is a recurring finding in studies of Chinese Americans [36-38] and other Asian American communities [39], such as Vietnamese Americans [33, 40] and Korean Americans [41, 42], with tangible consequences for the well-being of the patient as well as the caregiver. Chinese Americans also faced practical challenges in accessing appropriate resources, the most significant being language barrier [35].

Other ethnic minorities in the United States have been studied as well. For instance, a study contrasted patient and caregiver goals of English speaking and Spanish speaking individuals, exploring cultural differences in their concerns and expectations [43]. Many similar studies on the cultural differences of ethnic minorities of the United States have been carried out [44, 45]. Similar investigations on cultural disparities in persons affected by dementia have been conducted in the rest of the world. For instance, in the United Kingdom, minority ethnic caregivers tended to normalize dementia as a normal part of aging and showed poor understanding what local services could offer [46]. Likewise, in Denmark, Polish, Turkish and Pakistani immigrants lacked knowledge or misperceived dementia, which hampered timely access to services [47]. Israeli-Arab informal caregivers experienced stigmatization particular to their local cultural milieu [48]. These are but a few examples of this type of research.

Cultural diversity affects care and care delivery

The cross-cultural performance of **clinical tools** in dementia care has been questioned and investigated for many years [27]. For instance, select diagnostic tools have been accused of poor generalizability to minority ethnic groups, though socioeconomic status may be a cofounder in some cases [49]. Translated, adapted and new instruments aiding in diagnosis and management of dementia have been continuously developed and validated for ethnic groups worldwide.

American studies have examined differences in **clinical outcomes** between ethnic groups [27]. For example, one study highlighted the differences in the initiation and discontinuation of dementia medication between Black, Hispanic and White patients [27-30, 50-52]. Meanwhile, research on inequalities in clinical outcomes has been ongoing internationally. For example, a Danish study and a Norwegian study both indicated that immigrants were less likely to be treated pharmacologically [51, 52].

There has also been research exploring **service provider factors** when caring for ethnic minority dementia patients. For example, a study linked the nursing assistant's style of communication to variations in the behavioral symptoms of Korean American dementia patients [53]. Other studies investigated the ethnocultural diversity of service providers and how it may affect dementia care. For example, an Israeli study revealed significant differences in views towards the dementia patient's dignity and autonomy between the Jew, Arab and Russian staff of nursing homes [54].

More broadly, **barriers and facilitators in access to dementia care** by ethnic minorities have been studied in depth [55-58], though these studies are inevitably and intimately tied to the local population, healthcare system and even sociopolitical context.

Research has been done to evaluate **culturally tailored interventions** towards a specific ethnic group. For instance, a short film was created to educate Chinese Americans on dementia and address stigmatization of the condition, with some success [38]. A review on interventions for Hispanic informal caregivers in the United States emphasized the heterogeneity within Hispanics, and the importance for better understanding of Hispanic or Latino subcultures [59].

The state of scientific literature on dementia and culture and its message

There is a wealth of information available on the topic of dementia and culture [27]. There are thousands of studies of different types and different methodologies, that were conducted in different settings and with different populations seeking to describe the interplay between dementia and culture from a particular perspective. However, most conclusions drawn from the studies were anchored in the study's local reality, and more often than not, they cannot find direct application too far outside the study's locale. While valid and relevant, existing findings must be interpreted contextually and are rarely transferable to our local practices.

Furthermore, despite the number and variety of existing studies on dementia and culture, none examined the patients' and caregivers' cultural diversity in the context of dementia case management.

iii. On case management and culture: cultural competency is intrinsic to good case management

Case managers and studies of case management have reported on **the cultural differences of their service users**, detailed how these differences affect care and outcomes, and advocated for cultural competency. For instance, in a Toronto study on the balance of informal and formal care of the elderly, case managers noted different cultural understandings of and expectations towards caregiving, which in turn influenced the patient's and caregiver's help seeking behaviors [60]. To guide case managers, experts have authored recommendations for working with a particular ethnic group (e.g. Mexican American elders [61], or Chinese Americans[62]). For instance, Aleman et al. proposed a construct of four levels of assimilation of elderly Mexican Americans, which guides the case manager in tailoring their plan for a client [61]. Mukai introduced key ideas of the Chinese American identity relevant to healthcare delivery, and contrasted them with Western traditions and thoughts: dependence/independence, food, money, health/illness, conflict resolution, decision making, education; from these, Mukai derived recommendations to the case manager when working with Chinese Americans [62]. More broadly, authors formulated frameworks for delivering culturally competent case management [63]. In fact, a chapter of the Case Manager's Handbook is dedicated to the topic, culminating in the definition of cultural competency and how it translates into case management practices [15].

Conversely, studies have produced evidence supporting **case management as a particularly effective model of care for ethnic minorities**, for example in treating depression [64], in following up abnormal mammograms [65] and in managing type 2 diabetes [66].

Ethnic matching is a recurring topic of study in cultural case management. It is a process by which a service provider is matched with a service user of similar ethnocultural background. Ethnic matching has enjoyed some success and popularity in psychology and psychiatry, including in the context of mental health case management, where matching resulted in greater medication compliance [67] and less need for crisis interventions [68]. However, conflicting evidence exists, where matching the case manager to the patient by ethnicity resulted in no appreciably different outcomes [69, 70], or even worsened outcomes [71]. Study of ethnic matching in case management contributed towards more recent trends that emphasize on a more nuanced understanding of cultural differences and increased cultural training [72].

In short, existing literature shows that case managers recognize the cultural diversity of their clientele as an important factor in the delivery of appropriate and effective care. Beyond ethnic matching, case managers value cultural competency as being essential to successful case management. Conversely, evidence had demonstrated case management's effectiveness as a care model for chronic illnesses in ethnic minority populations. However, no study of case management from an ethnocultural perspective was done in the context of dementia care, which would add its own unique challenges to the equation.

b. Summary of Knowledge Gap

In summary, there is a wealth of relevant scientific literature on dementia, case management and culture. Studies of dementia case management revealed variability in the implementation of the care model, but promise in achieving better clinical outcomes than standard or usual care. Research on dementia and culture often narrowed down to one or two distinct ethnic groups in a well-defined context of study in order to draw meaningful, actionable conclusions. Previous work on case management and culture highlighted the importance of adapting for the cultural diversity of the service users to case manage successfully. However, no single work encompassed all three elements of interest at once [24] (Figure 1).

Additionally, our study context, a Montreal Family Medicine Group, is peculiar enough to pose serious barriers in integrating and applying of current knowledge.

For instance, while the United States and the province of Quebec are both home to Chinese immigrants, we may not be able to make use of existing American studies because the broader social context (particularly the bilingualism in Montreal), the healthcare system and even the individuals themselves are too different. We operate under a specific, tense sociopolitical climate, as exemplified by debates surrounding reasonable accommodation, the extent to which society should adjust to the demands of minority groups without compromising equal opportunity [73].

In addition to personal experiences, we believe there is risk that some inequality can exist in our dementia care environment, especially when culturally diverse patients undergo the serious and complex interactions that form the process of case management. To justify and improve the current standard of practice in dementia case management, it is essential to uncover and document problems and needs particular to culturally varied individuals of this patient population, issues that may be unaddressed or even unheard. As existing evidence cannot provide such answers, our exploratory, pilot study begins to fill the gap by investigating case management of culturally diverse persons affected by dementia, highlighting the patients' and caregivers' perspectives, set in our local clinical practices.

c. Specific Objectives

1. To determine the ethnocultural diversity of community-dwelling dementia patients and their informal caregivers cared for through primary care case management in one Family Medicine Group
2. To determine if ethnoculturally distinct groups of these service users have different needs and problems

d. Research Questions

1. What are the sociodemographic, ethnocultural, memory and health characteristics of community-dwelling dementia patients and informal caregivers cared for through primary care case management at the Herzl Family Practice Centre?
2. What are the needs and problems of these patients and caregivers?
3. What are the sociodemographic, memory and health characteristics of Canadian born vs. foreign born patients and caregivers?
4. What are the needs and problems of Canadian born vs. foreign born patients and caregivers?

Chapter 3: Methods

a. Study Design

We conducted a cross-sectional study of dementia patients and their informal caregivers. This was an exploratory, pilot study.

b. Study Settings

The present research focused on one Family Medicine Group that adopted case management for its dementia patient population following the Quebec Alzheimer Plan. It is the Herzl Family Practice Centre, Jewish General Hospital, located in the borough of Côte-des-Neiges–Notre-Dame-de-Grâce in Montreal. Indeed, the study site is the first of 6 sites to be researched in a larger project led by the supervisors of the present thesis.

c. Study Population

i. Target population of interest

The study's population of interest was mild cognitive impairment or mild to moderate dementia patients and their informal caregivers living in the community, cared for through primary care case management at the Herzl Family Practice Centre.

ii. Eligibility criteria

Inclusion criteria for patients were as follows: patient suffers mild cognitive impairment (MCI) [74, 75] or mild to moderate dementia [75, 76] (Mini-Mental State Examination (MMSE) above 16 and Montreal Cognitive Assessment (MoCA) above 10, so as to gain information directly from the patient) [77-79]; patient is not terminally ill; patient resides in the community; patient has an eligible informal caregiver.

Exclusion criteria for patients were as follows: patient suffers from severe dementia [75, 76]; suffers from dementia secondary to alcohol abuse, HIV/AIDS or brain tumor; is not able to consent; suffers from any comorbidity deemed terminal; lives in a nursing home or assisted living facility; has no eligible informal caregiver.

Inclusion criteria for the informal caregivers were as follows: caregiver is a primary contact in the patient's records, and/or accompanies the patient regularly to medical visits, and/or spends at least four hours per day, four days per week in direct contact with the patient unpaid.

Exclusion criteria for the informal caregivers were as follows: none.

d. Data Collection and Measurement Tools

i. Questionnaires

Patient's and caregiver's sociodemographic and ethnocultural characteristics: in-house questionnaire

Consulting the Canadian census as a reference for format and reporting standards [22], we used an in-house questionnaire to collect the patient's and the caregiver's sociodemographic information: age, sex, highest level of education completed, labour force status and work activity. In addition, we took note of the relationship between the patient and the caregiver.

Also using the Canadian census as a reference, we collected their ethnocultural information: country of birth, year of immigration, self-identification of ethnic origins, self-identification as a visible minority, legal status in Canada, languages spoken and spiritual beliefs.

Patient's memory and health: MMSE, MoCA, NPI and QOL-AD

To begin describing the characteristics of their memory decline, we asked the patient when the memory problems first appeared, and their answer was always corroborated by their informal caregiver.

We assessed the patient's cognitive impairment using the Mini-Mental State Examination (MMSE). Created in 1975 by Folstein et al., the MMSE has been validated and applied extensively in clinical practice and research settings, and remains in popular usage today [80, 81]. The MMSE is composed of 11 questions or tasks assessing five areas of cognitive function: orientation, registration, attention and calculation, recall and language [80, 81]. The maximum score is 30 [80, 81]. The MMSE takes about 5 to 10 minutes to administer [80, 81].

We also assessed the patient's cognitive impairment using the Montreal Cognitive Assessment (MoCA). The MoCA is a newer, more challenging test developed to surpass the MMSE in detecting mild cognitive impairment (a clinical state that often progress to dementia) and was published in 2005 by Nasreddine et al. [82]. Since its creation, numerous studies have confirmed its increased sensitivity in detecting the early stages of cognitive decline, and today, the MoCA is widely used clinically and in research [83-86]. The MoCA covers eight cognitive domains: visuospatial/executive, naming, memory, attention, language, abstraction, delayed recall and orientation [82]. The maximum score is 30 [82]. The MoCA takes about 10 minutes to administer [82-86].

We also described the behavioral manifestations of dementia of patients by administering the Neuropsychiatric Inventory (NPI). The NPI was first developed and validated in 1994 by Cummings et al. [87]. NPI was initially composed of 10 domains, each representing a neuropsychiatric disturbance commonly observed in dementia such as agitation, dysphoria, anxiety and apathy [87]. 2 domains were added later on in 1997, being night-time behavioral disturbances and appetite and eating abnormalities [88]. The NPI is administered to the patient's caregiver, preferably in the absence of the patient to facilitate an open discussion [87, 88]. For each domain, there is a screening question; if a domain is revealed to be problematic, additional questions are asked [87, 88]. The caregiver is asked to rate the frequency of symptoms on a 4 point scale and the severity of symptoms on a 3 point scale, with the total score for a given domain being the product of the symptoms' frequency and severity [87, 88]. A total NPI score is generated by adding each domain's total score [87, 88]. Additionally, for each domain, the caregiver is also asked to rate the distress that the symptom causes them on a 5 point scale, a feature added later on in 1998 [89]. A total distress score is calculated by adding each domain's distress score [89]. Importantly, all questions in the NPI pertain to changes in the patient's behavior that have appeared since the onset of dementia [87-89]. The NPI has been widely distributed, and has been further developed, with an abridged clinical version and a diary version appearing among others [90, 91]. Its various versions have been validated cross-culturally across the globe [92-99].

We also measured the patient's quality of life, by administering the Quality of Life – Alzheimer's Disease scale (QOL-AD). The QOL-AD was developed and validated in 1999 by Logsdon et al. to assess perceived quality of life in Alzheimer's disease (later in 2002 in cognitive impairment as well), encompassing the interpersonal, environmental, functional, physical and psychological domains of a person [100, 101]. QOL-AD is composed of 13 items, rated separately by the patient and by their informal caregiver on a 4 point scale, with 1 being poor and 4 being excellent [100, 101]. The total QOL-AD score, then, ranges from a minimum of 13 to a maximum of 52 [100, 101]. The use of QOL-AD is reported extensively in the literature, for example, in validation studies for localization to a particular language or country [102-105], in the comparison of patient and caregiver reported scores [106, 107], in the comparison of scores reported by different types of caregiver [108]. QOL-AD's performance has been validated in a variety of settings such as in hospital [109] or in clinical trials [106, 110], for patients ranging from cognitive impairment to severe dementia [100, 101, 110, 111].

Patient's needs: CANE

To systematically assess the patient's needs, we used the Camberwell Assessment of Need for Elderly (CANE). CANE was developed and validated in 2000 by Reynolds et al. to provide a comprehensive evaluation of the needs of the elderly with mental disorders [112]. Based on the Camberwell Assessment of Need (CAN), seven new items were added with two old items removed to form the CANE, totaling 24 items that detail the patient's daily living, ranging from accommodation, food to memory, physical health, drugs, etc. [112]. For each item, the patient can express having "no need" in that area, having a need but it is being dealt with adequately (defined as a "met need"), or having a need that is not sufficiently addressed (defined as a "unmet" need) [112]. For each need, met or unmet, the patient is asked about the level of informal help (from relatives and friends) and formal help (from local services) they receive; how much formal help they think is needed; whether they believe they are receiving the right type of help; whether they are satisfied with the amount of help received [112]. In addition to the patient's perspective, CANE allows us to record the informal caregiver's answers to each question as well as the rater's (the researcher's or the interviewer's) clinical judgement [112]. CANE has been validated for clinical practice as well as for research [112, 113]. In addition to further validation studies e.g. localized versions [114-117], researchers have applied CANE in the study of the needs of various elderly population in various settings, such as community dwelling dementia patients [118, 119], dementia patients in care homes [120], elderly mental health patients [121, 122] and elderly patients frequenting primary care, nursing care or long-term care [123-125].

Caregiver's problems and needs: CNA-D

To systematically assess the caregiver's problems and needs, we used the Carers' Needs Assessment for Dementia (CNA-D). CNA-D was developed and validated in 2005 by Wancata et al. as an instrument to assess the needs of caregivers of dementia patients are met, for the purposes of service planning [126]. The CNA-D is composed of 18 problem areas a caregiver may be experiencing, with an optional area for additional problems not already listed [126]. Problem areas range from lack of information about dementia, about treatment, about services, to social isolation, feelings of guilt, burn out, and physical and mental health of the caregiver [126]. For each area, both the caregiver and the interviewer rate the problem as being absent or mild, moderate, serious [126]. Under each problem area, CNA-D lists possible interventions that may be helpful, whether they are available locally or not [126]. In total across the questionnaire, CNA-D proposes 24 potential caregiver resources, such as counselling, support from a social worker, diagnosis or treatment by a general practitioner and psychotherapy [126]. If a problem is deemed moderate or serious, both the caregiver and the interviewer determine whether a possible intervention is needed or not [126]. The rating of need for a particular service or resource is defined and coded based on a prior framework of needs [126, 127], as following: “no need”, where an intervention is not needed and not received; “overprovision”, where an intervention is not needed but received anyways; “unmet need”, where an intervention is needed but not received; “partially met need”, where an intervention is needed and received, but insufficiently or inadequately; “met need”, where an intervention is needed and sufficiently received [126]. While the caregiver’s answer to a question is written down as it is, the interviewer takes into account what was communicated over the entire conversation and uses clinical judgement in formulating their assessment of a problem or need [126]. Lastly, the carer is also asked for their level of satisfaction for the help and support offered to them for a given problem [126]. CNA-D is validated for both clinical use and research purposes [113, 126]. However, to our best knowledge, we will be among the first to apply CNA-D and report its use.

ii. Review of electronic medical records

Furthermore, with the patient’s permission, we conducted a chart review of their electronic medical records at the Herzl to assess whether they were treated pharmacologically for their memory symptoms with a cholinesterase inhibitor, as indicated for dementia in the Canadian clinical guidelines [128-130].

To describe the patient’s overall health issues, we measured the number of comorbidities and active medications per patient in the same chart review.

e. Study Process

i. By telephone: recruitment

Study recruitment began in June 2018 and ended in February 2019.

The Herzl Family Practice Centre provided a list of patients who complained of and were investigated for memory deficits. The patients' family physicians gave consent to contact their patients. We attempted to recruit all patients and their informal caregivers. Patients and/or their informal caregivers were telephoned, and the study was explained to them in lay terms. If interested, an appointment was taken to meet in person with both the patient and the caregiver to proceed further in the study. This took place either at the Department of Family Medicine, Faculty of Medicine, McGill University or at the patient's home depending on their preference.

To track recruitment, we came to adopt a system imitating those used in professional market research, recording date and time of call, detailing what happened during the call and formulating a plan of action. For example, the patient's son answered and suggested to call back in two weeks because the patient is travelling. Or for example, there was no answer, so we should try to call at a different time of the day or a different day of the week.

For about the first four months of recruitment, we attempted to contact almost daily the patients who did not answer. For the following months until the end of recruitment, we attempted to contact those patients four times a week: in the day and in the evening on a weekday, and in the day and in the evening on the weekend.

We also called the patients and/or caregivers who initially refused to participate about four months later to see if they had changed their minds.

ii. In person: consent, eligibility and questionnaires

In person, we reviewed the consent forms together with the participants, and we obtained informed consent of both the patient and the caregiver. This included the patient's permission for the researchers to access their electronic medical records at the Herzl Family Practice Centre. This step took about 10 minutes per visit.

Then, eligibility of the patient and the caregiver were assessed. At this stage, MMSE and MoCA were administered to the patient. This step took about 20 minutes per visit.

If eligible, we inquired about the onset of the patient's memory symptoms, and took note of the patient's and the caregiver's background information, i.e. sociodemographic and ethnocultural characteristics. This step took about 10 minutes per visit.

Then, questionnaires were administered. CANE was administered by the researcher to both the patient and the caregiver. QOL-AD was given to the patient and the caregiver to complete individually, after explanation by the researcher. Afterwards, NPI and CNA-D were administered by the researcher to the caregiver alone. This step took between 45 and 90 minutes.

The order in which different types of data were collected was to allow the in-person visit to flow naturally, and does not mirror the order of our research questions or our reporting of study results.

iii. Electronic medical records review

After the in-person meeting, we conducted a chart review of the recruited patients' electronic medical records at the Herzl Family Practice Centre. We reviewed and collected information on their comorbidities and medications.

f. Outcome Variables

i. To answer research questions 1 and 3: assessment of sociodemographic, ethnocultural, memory and health characteristics

Our first and third research questions are on the background of our study participants. We can further divide the questions into the smaller sub-questions of sociodemographic, ethnocultural, memory and health characteristics (Table 1).

To describe the sociodemographic characteristics of the patients and caregivers, we measured age, sex, highest level of education completed, labour force status and work activity, relationship between patient and caregiver.

To describe the ethnocultural characteristics of our patients and caregivers, for the first research question, we documented country of birth, age at immigration to Canada, self-identification of ethnic origins, self-identification as a visible minority, legal status in Canada, languages spoken and spiritual beliefs. For the third research question, since country of birth becomes an explanatory variable, we measured the patients' and caregivers' self-identification of ethnic origins, self-identification as a visible minority, languages spoken and spiritual beliefs to describe their ethnocultural characteristics.

Table 1. Matching research questions to variables

Research questions	Sub-questions	Outcome variables	Explanatory variable
1. What are the sociodemographic, ethnocultural, memory and health characteristics of community-dwelling dementia patients and informal caregivers cared for through primary care case management at the Herzl Family Practice Centre?	Sociodemographic (patient and caregiver)	Age Sex Highest level of education completed Labor force status and work activity Relationship between patient and caregiver	N/A
	Ethnocultural (patient and caregiver)	Country of birth Age at immigration to Canada of foreign born persons Visible minority Languages spoken Spiritual beliefs	
	Memory (patient)	Self-reported onset of symptoms in years MMSE score MoCA score Prescribed a cholinesterase inhibitor 12 item NPI score and caregiver distress score	
	Health (patient)	Number of comorbidities Number of active medications QOL-AD score	
2. What are the needs and problems of these patients and caregivers?	Needs (patients)	CANE number of met, unmet and total patient needs as well as profile of needs	N/A
	Problems and needs (caregivers)	CNA-D number and profile of caregiver problems CNA-D number of met and unmet needs as well as profile of caregiver needs	
3. What are the sociodemographic, memory and health characteristics of Canadian born vs. foreign born patients and caregivers?	Sociodemographic (patient and caregiver)	Age Sex Highest level of education completed Labor force status and work activity Relationship between patient and caregiver	Born in Canada vs. outside of Canada
	Ethnocultural (patient and caregiver)	Visible minority Languages spoken Spiritual beliefs	
	Memory (patient)	Self-reported onset of symptoms in years MMSE score MoCA score Prescribed a cholinesterase inhibitor 12 item NPI score and caregiver distress score	
	Health (patient)	Number of comorbidities Number of active medications QOL-AD score	
4. What are the needs and problems of Canadian born vs. foreign born patients and caregivers?	Needs (patients)	CANE number of met, unmet and total patient needs as well as profile of needs	Born in Canada vs. outside of Canada
	Problems and needs (caregivers)	CNA-D number and profile of caregiver problems CNA-D number of met and unmet needs as well as profile of caregiver needs	

To describe the characters of our patients’ memory decline, we measured the self-reported onset of memory symptoms, their MMSE score, their MoCA score, whether they were prescribed a cholinesterase inhibitor and their 12 item NPI score and caregiver distress score.

To describe the overall health characteristics of our patients, we measured the number of comorbidities and the number of active medications, as well as QOL-AD scores.

ii. To answer research questions 2 and 4: assessment of needs and problems

To describe the needs of patients, we collected, analyzed and reported the number of met, unmet and total patient needs using CANE, as well as generated a profile of patient needs.

As for the caregivers, we used CNA-D to collect, analyze and report the number of caregiver problems and generate a profile of caregiver problems. Also using CNA-D, we collected, analyzed and reported the number of met and unmet caregiver needs for services, and generated a profile for those needs.

g. Explanatory Variable

For the explanatory variable in research questions 3 and 4, we divided our study sample into two distinct ethnocultural groupings of participants: those born in Canada, and those born outside of Canada (Table 1).

When planning the study, we contemplated dividing the groups of analysis by the ethnic origins of our participants to fully reflect the richness of our local cultural context. However, we were concerned that doing so would result in too many groups, with many groups having perhaps one or two participants. At the same time, we had anticipated the frailty of the patients and the low response rate in a study population already limited in size. To make comparisons from the available data (albeit still not statistically significant), we refrained from overly fragmenting our small sample size. Happily, in our case, classifying participants by their country of birth (Canada against not Canada) established two ethnoculturally distinct groups and allowed for meaningful conclusions to be drawn.

h. Data Analysis

To answer research question 1, we used descriptive statistics to report the sociodemographic, ethnocultural, memory and health characteristics of dementia patients and their informal caregivers.

To answer research question 2, we used descriptive statistics to report the patient needs (CANE summary scores and profiles using the patient's, caregiver's and researcher's answers), and caregiver problems and caregiver needs (CNA-D summary scores and profiles using the caregiver's and the researcher's answers). For continuous variables such as age, onset of memory symptoms and questionnaire scores, we report the mean, the standard deviation (sd) and the range.

For categorical variables such as sex and education, we report the number and percentage of participants per category.

To answer research questions 3 and 4, we stratified our study sample by country of birth (born in Canada vs. outside Canada). Due to the small sample size, no statistical testing was conducted. Indeed, our starting study population was limited in size and we had anticipated low response rates due to the frailty of the patients. Comparisons of findings hereafter are simple mathematical inequalities (side by side or eye comparison) and are hypothesis generating.

i. Ethics

The larger multisite study, under which the present thesis work was conducted, was approved by the research ethics committee of the Jewish General Hospital, Montreal (Project MP-05-2019-1462, see Appendix I).

Our work involved dementia patients and their informal caregivers, who are often considered vulnerable adult individuals, as well as marginalized ethnic groups within that patient population. Administering questionnaires may have caused some psychological distress, because the participants were sometimes asked to remember difficult moments or painful experiences. However, discussing with a researcher (a third party, an outsider) may have proven therapeutic as well, providing an opportunity to gain perspective in their journey. We offered study results to participants who displayed interest; to realize that issues important to them have been recognized or that others share similar experiences may be an empowering experience. In addition, participants may one day benefit from changes in clinical practices informed by the study. Thus, potential benefits outweigh potential risk.

Nonetheless, the following measures were taken to minimize risk.

We obtained informed consent from both the patient and their informal caregiver. When first meeting in person, before data collection began, researchers or assistants reviewed the consent form with the participants, making sure that all parties understand the study purpose, the procedures, risks and benefits, our roles as researchers independent from their care, voluntary participation and withdrawal at any time, and confidentiality. We also asked for the patient's permission to access their electronic medical records at the Herzl, in order to collect data on comorbidities and medications. We did not accept consent by proxy, because only patients suffering from mild to moderate dementia were eligible for the present study.

On confidentiality, we assigned a personal identification number (PIN) to patients and caregivers. The list linking the PIN to a participant was only available to the researcher on a password protected computer. We removed all other identifying information after data collection: data was entered and analyzed anonymously on password protected computers, and were also reported anonymously to protect the confidentiality of our participants.

All physical files were kept in a locked cabinet in a locked suite at the Department of Family Medicine, Faculty of Medicine, McGill University. All digital material was kept on password protected computers.

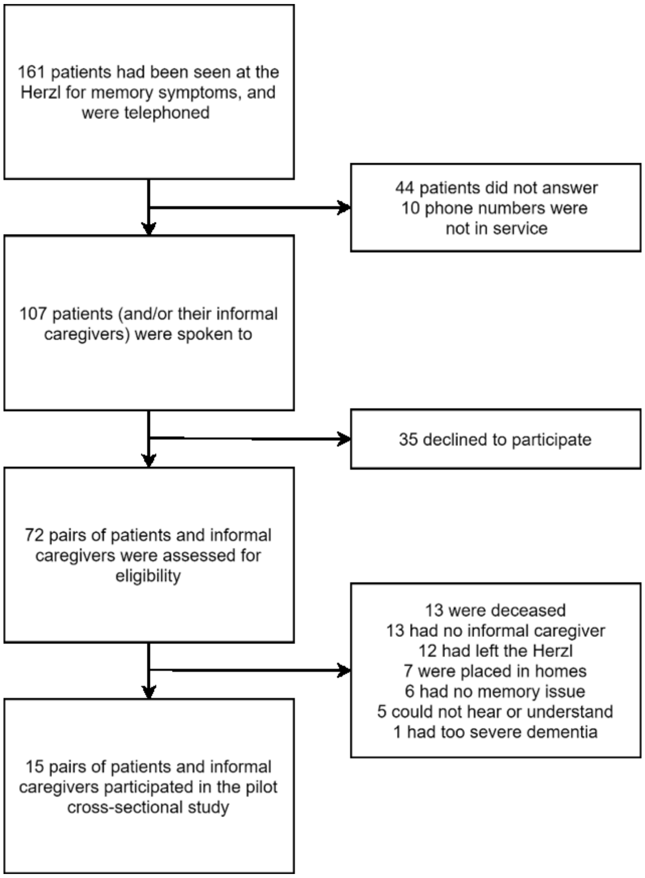
Chapter 4: Results

a. Answering Research Question 1: Sociodemographic, Ethnocultural, Memory and Health Characteristics of Patients and Caregivers

i. Recruitment of study participants

161 patients of the Herzl Family Practice Centre had a clinical visit for memory issues, mild cognitive impairment or dementia over the past three years. We telephoned all 161 patients, of which 44 did not answer and 10 phone numbers were not in service. We reached 107 patients and/or their informal caregivers, of which 35 declined to participate. We assessed the eligibility of 72 pairs of patients and caregivers: 13 patients were deceased, 13 others had no informal caregiver, 12 had left the Herzl, seven were placed in nursing homes or other long-term care facilities (i.e. no longer lived in the community), six had no memory issue, five could not hear or understand, one had too severe dementia. Ultimately, 15 pairs of patients and informal caregivers participated in the present study (Figure 2).

Figure 2. Recruitment of study participants at the Herzl Family Practice Centre



ii. Sociodemographic characteristics of patients and caregivers

Our sample was composed of 15 patients aged on average 76.5 years (sd: 9.2, range: 61-91) of which 10 men formed a small majority (66.7%) (Table 2b). Contrastingly, the 161 patients telephoned were on average 80.1 years old (10.8, 41-102), with 76 men forming a big minority (47.2%) (Table 2a). By removing 57 ineligible patients, we had on theory 104 patients potentially eligible for the study (but some refused, or we could not contact them): these patients were on average 79.1 years old (10.2, 54-102), with 56 men forming a small majority (50.9%) (Table 2a).

Table 2a. Age and sex of patients the study attempted to recruit, potentially eligible patients and patients enrolled in the study

	161 patients telephoned	104 patients who were potentially eligible	15 patients enrolled in the study
Age (mean, sd, range)	80.1 (10.8, 41-102)	79.1 (10.2, 54-102)	76.5 (9.2, 61-91)
Sex, male (number, %)	76 (47.2%)	56 (50.9%)	10 (66.7%)

Three patients (20.0%) did not receive a high school diploma while eight did (53.3%), with the remaining four completing a post-secondary degree (26.7%) (Table 2b). All but one patient was retired, with the exception being a patient working full-time (Table 2b).

Our sample of 15 caregivers aged on average 72.3 years (12.5, 41-90) with a female majority of 12 women (80.0%) (Table 2b). Four caregivers did not complete secondary education (26.7%), Four did (26.7%), with seven others having completed a higher degree (46.7%) (Table 2b). Among the caregivers, a majority of 11 were retired (73.3%), with one working part-time (6.7%) and the remainder three working full-time (20.0%) (Table 2b).

The caregivers were almost always the spouse or the partner of the patient (93.3%), except in one case where it was a parent-child relationship (6.7%) (Table 2b).

iii. Ethnocultural characteristics of patients and caregivers

10 patients (66.7%) were born outside Canada, originating from nine different countries: Egypt, France, Haiti, Italy, Jamaica, Morocco, the Philippines and South Africa each contributed one patient, in addition to two patients born in the United States (Table 2b). Foreign born patients immigrated to Canada on average at the age of 36.7 years (16.9, 18-66). Patients reported 10 different ethnic origins; though we allowed for multiple responses per patient, every patient reported only one ethnic origin. 3 patients self-identified as a visible minority (20.0%).

Table 2b. Sociodemographic and ethnocultural characteristics of patients and their informal caregivers (patients n=15, caregivers n=15)

	Patient	Caregiver
Age (mean, sd, range)	76.5 (9.2, 61-91)	72.3 (12.5, 41-90)
Sex, male (number, %)	10 (66.7%)	3 (20.0%)
Highest level of education completed		
Below high school	3 (20.0%)	4 (26.7%)
High school or apprenticeship	8 (53.3%)	4 (26.7%)
College, CEGEP, university and above	4 (26.7%)	7 (46.7%)
Labor force status and work activity		
Retired (number, %)	14 (93.3%)	11 (73.3%)
Working part-time (number, %)	0 (0.0%)	1 (6.7%)
Working full-time (number, %)	1 (6.7%)	3 (20.0%)
Relationship between patient and caregiver		
Couple (number, %)	14 (93.3%)	
Parent-child (number, %)	1 (6.7%)	
Other (number, %)	0 (0.0%)	
Ethnocultural characteristics		
Born outside Canada (number, %)	10 (66.7%)	9 (60.0%)
Country of birth	Canada=5 Egypt=1 France=1 Haiti=1 Italy=1 Jamaica=1 Morocco=1 Philippines=1 South Africa=1 United States=2	Canada=6 Egypt=1 France=1 Guyana=1 Italy=1 Jamaica=1 Morocco=2 Philippines=1 United States=1
Age at immigration to Canada of foreign born persons (mean, sd, range)	36.7 (16.9, 18-66)	34.3 (13.3, 23-65)
Ethnic origins	"Caucasian"=2 "Filipino"=1 "French"=2 "French Canadian"=1 "Haitian"=1 "Italian"=1 "Jamaican"=1 "Jewish"=4 "Quebecer"=1 "South African"=1	"Afro American"=1 "Albanian-Canadian"=1 "Canadian"=2 "Caucasian"=1 "Filipino"=1 "French"=2 "Italian"=1 "Italian-Canadian"=1 "Jamaican"=1 "Jewish"=3 "Quebecer"=1
Visible minority (number, %)	3 (20.0%)	3 (20.0%)
Legal status		
Canadian citizen (number, %)	14 (93.3%)	14 (93.3%)
Permanent resident (number, %)	1 (6.7%)	1 (6.7%)
Knowledge of official languages of Canada (French and English) and other languages		
No knowledge of official language (number, %)	0 (0.0%)	0 (0.0%)
Unilingual, speaks one official language (number, %) speaks only French (number, %) speaks only English (number, %)	8 (53.3%) 4 (26.7%) 4 (26.7%)	8 (53.3%) 3 (20.0%) 5 (33.3%)
Bilingual, speaks French and English (number, %)	7 (46.7%)	7 (46.7%)
Speaks foreign language(s) natively (number, %)	6 (40.0%)	7 (46.7%)
Spiritual beliefs		
Agnosticism or atheism (number, %)	5 (33.3%)	4 (26.7%)
Christianism (number, %)	6 (40.0%)	8 (53.3%)
Judaism (number, %)	4 (26.7%)	3 (20.0%)

14 patients were Canadian citizens (93.3%), while one patient was a permanent resident. Though all 15 patients (100.0%) could at least speak one official language (English or French), a small majority of eight patients (53.3%) only knew either English or French. Six patients (40.0%) spoke a foreign language natively. The patients' spiritual or religious beliefs fell into three broad categories: five patients were agnostics or atheists (33.3%), six were Christians (40.0%) and four were Jewish (26.7%).

Nine caregivers (60.0%) were born outside Canada, originating from eight different countries: Egypt, France, Guyana, Italy, Jamaica, the Philippines and the United States each contributed one caregiver, while two caregivers were born in Morocco (Table 2b). Foreign born caregivers immigrated to Canada on average at the age of 34.3 years (13.3, 23-65). Caregivers reported 11 different ethnic origins, though we allowed for multiple responses per caregiver, every caregiver reported only one ethnic origin. Three caregivers (20.0%) self-identified as a visible minority. 14 caregivers were Canadian citizens (93.3%), while one caregiver was a permanent resident. Though all 15 caregivers (100.0%) could at least speak one official language (English or French), a small majority of eight caregivers (53.3%) only knew either English or French. Nine caregivers (60.0%) spoke a foreign language natively. Caregivers' spiritual or religious beliefs fell into three broad categories: four caregivers were agnostics or atheists (26.7%), eight were Christians (53.3%) and four were Jewish (20.0%).

iv. Memory characteristics of patients

The onset of the patient's memory symptoms averaged 3.1 years (2.0, 1-9) (Table 3). The severity of symptoms was generally mild, with an average MMSE score of 27.0 (2.4, 21-30) and a MoCA score of 22.7 (3.4, 15-27), both instruments being out of 30 (Table 3). Five patients (30.0%) were prescribed a cholinesterase inhibitor (Table 3).

The behavioral manifestations of dementia, as measured by NPI by caregiver report, were rated on average 6.2 (7.7, 0-20) per patient (Table 3). Four patients experienced no behavioral symptoms at all, while five patients were symptomatic in just one domain. The remainder six patients were relatively more neuropsychiatrically affected. The most common complaints were "depression" (seven patients) and "sleep and nighttime behavior disorders" (six patients). The caregiver distress associated with these neuropsychiatric symptoms, also measured by NPI, was on average 3.5 (5.3, 0-20) per caregiver (Table 2b). Six caregivers reported no distress associated with the patient's behavioral symptoms, eight caregivers scored between 1 and 9 inclusively, and one caregiver scored 20.

Table 3. Memory and health characteristics of patients (n=15)

Patient’s memory issues	
Self-reported onset in years (mean, sd, range)	3.1 (2.0, 1-9)
MMSE (mean, sd, range)	27.0 (2.4, 21-30)
MoCA (mean, sd, range)	22.7 (3.4, 15-27)
Prescribed cholinesterase inhibitor (number, %)	5 (33.3%)
Neuropsychiatric Inventory (NPI)	
12 item NPI score (mean, sd, range)	6.2 (7.7, 0-20)
12 item caregiver distress score (mean, sd, range)	3.5 (5.3, 0-20)
Patient’s health	
Number of comorbidities (mean, sd, range)	4.5 (2.3, 1-8)
Number of active medications (mean, sd, range)	8.7 (2.3, 5-12)
Quality of Life in Alzheimer’s Disease (QOL-AD)	
Patient scoring of self (mean, sd, range)	38.8 (5.0, 28-46)
Caregiver scoring of the patient (mean, sd, range)	35.6 (8.3, 19-48)

v. Health characteristics of patients

On average, patients suffered from 4.5 other chronic conditions (2.3, 1-8) and were prescribed 8.7 medications (2.3, 5-12) (Table 3).

Patient’s self-reported quality of life using the QOL-AD scale was on average 38.8 (5.0, 28-46), out of a total of 52 (Table 3). The caregiver’s scoring of the patient, using the same scale, was on average 35.6 (8.3, 19-48) (Table 3).

b. Answering Research Question 2: Needs and Problems of Patients and Caregivers

i. Patient needs

Patients reported on average 3.7 met needs (1.8, 2-8) and 0.5 unmet needs (1.1, 0-4), as CANE revealed (Table 4). In order of decreasing prevalence, the following needs were most pressing: “memory” (mostly met), “physical health” (met), “money/budgeting” (mostly met), “eyesight, hearing, communication” (met), “drugs” (met), “psychological distress” (met) (Figure 3a-c, Appendix II). Patients received both formal and informal help in these areas (Figure 4).

Table 4. Camberwell Assessment of Need for the Elderly (CANE): Number of needs of patients (n=15)

Patient-reported number of met needs (mean, sd, range)	Patient-reported number of unmet needs (mean, sd, range)	Patient-reported total number of needs (mean, sd, range)
3.7 (1.8, 2-8)	0.5 (1.1, 0-4)	4.3 (1.8, 2-8)
Caregiver-reported number of met needs (mean, sd, range)	Caregiver-reported number of unmet needs (mean, sd, range)	Caregiver-reported total number of needs (mean, sd, range)
4.1 (1.8, 2-8)	0.7 (1.0, 0-3)	4.8 (2.1, 2-8)
Researcher-reported number of met needs (mean, sd, range)	Researcher-reported number of unmet needs (mean, sd, range)	Researcher-reported total number of needs (mean, sd, range)
4.1 (2.1, 1-9)	0.7 (1.3, 0-5)	4.8 (2.1, 2-10)

Figure 3a. CANE: Met and Unmet Needs of Patients, as Reported by the Patient, the Caregiver and the Researcher (n=15) (Part 1 of 3)

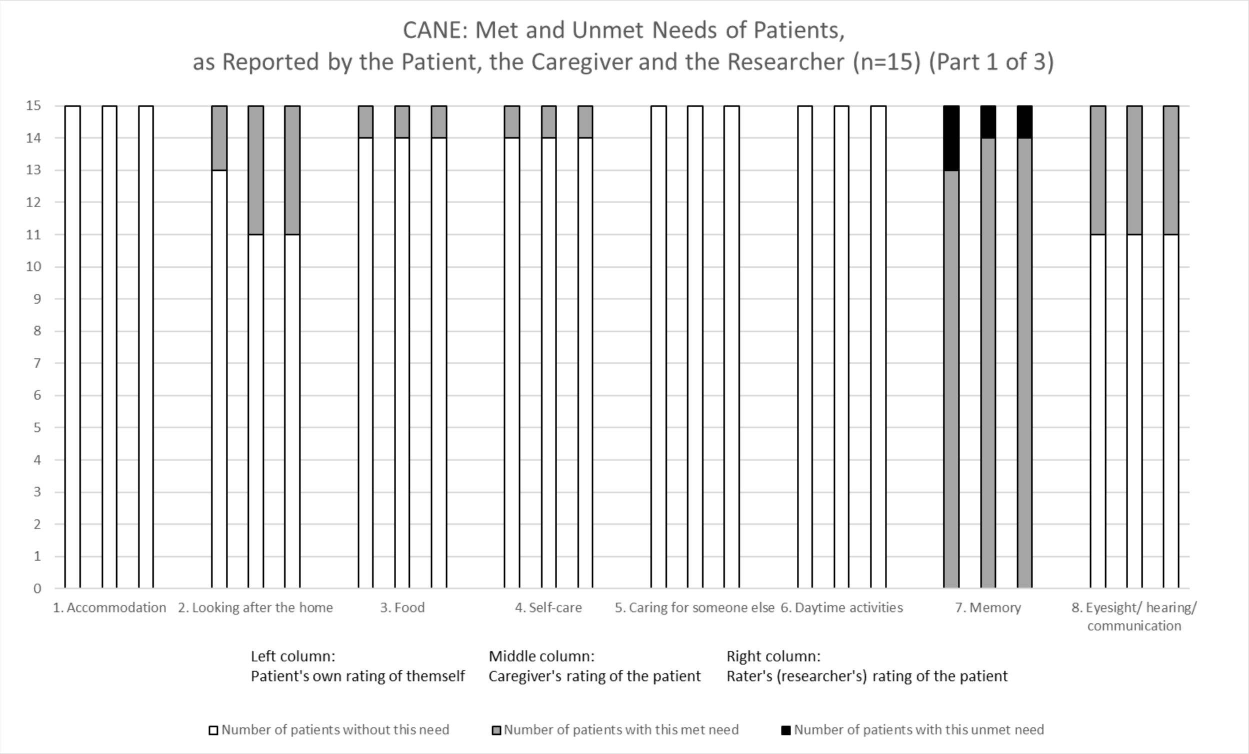


Figure 3b. CANE: Met and Unmet Needs of Patients, as Reported by the Patient, the Caregiver and the Researcher (n=15) (Part 2 of 3)

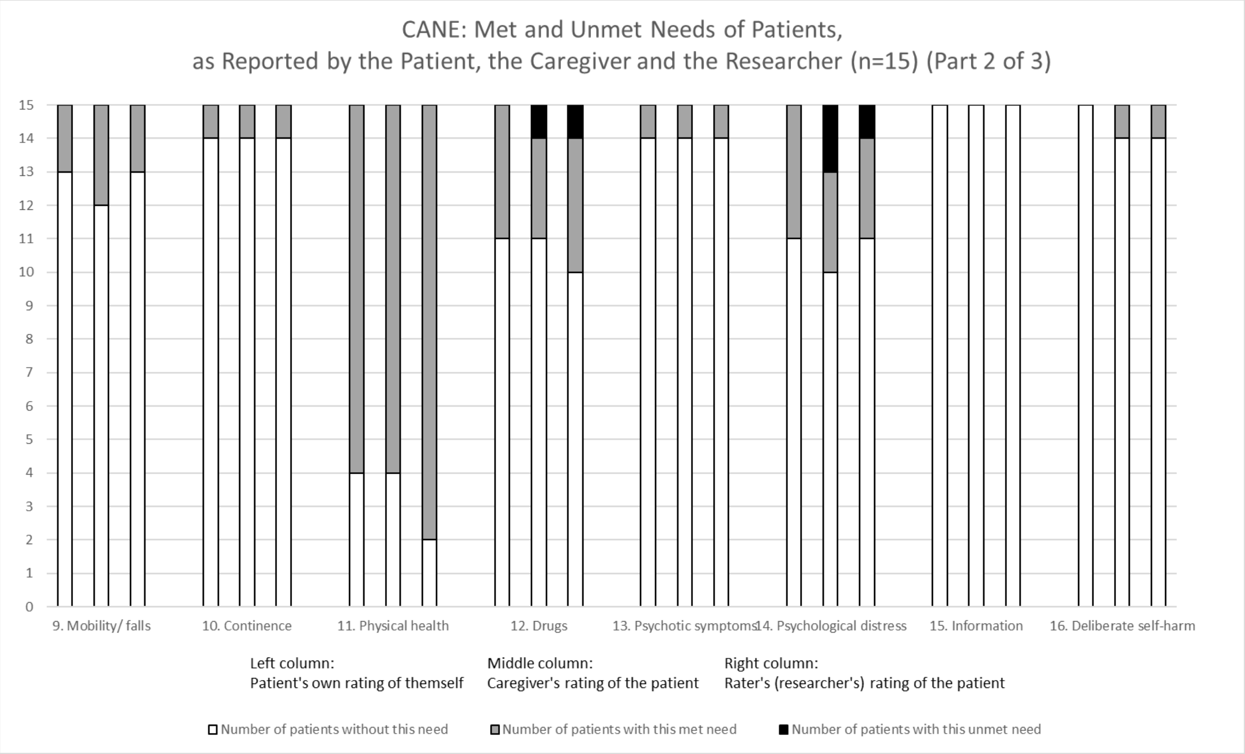


Figure 3c. CANE: Met and Unmet Needs of Patients, as Reported by the Patient, the Caregiver and the Researcher (n=15) (Part 3 of 3)

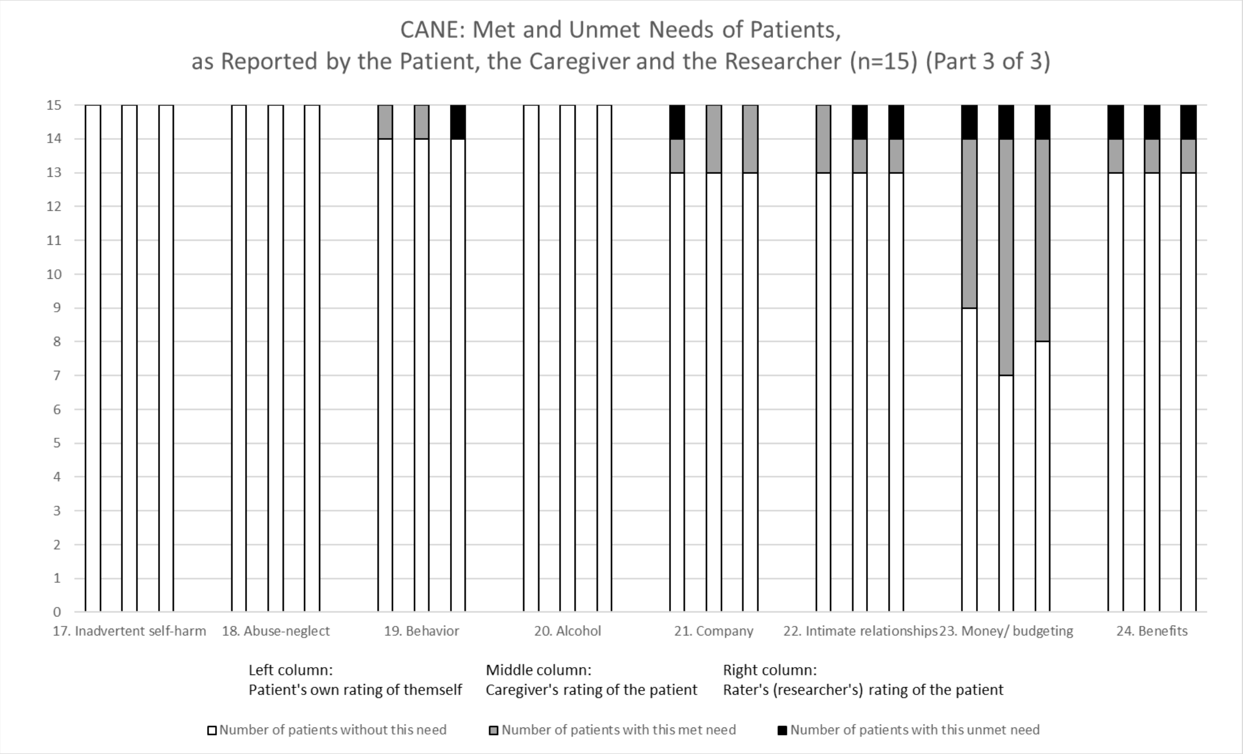
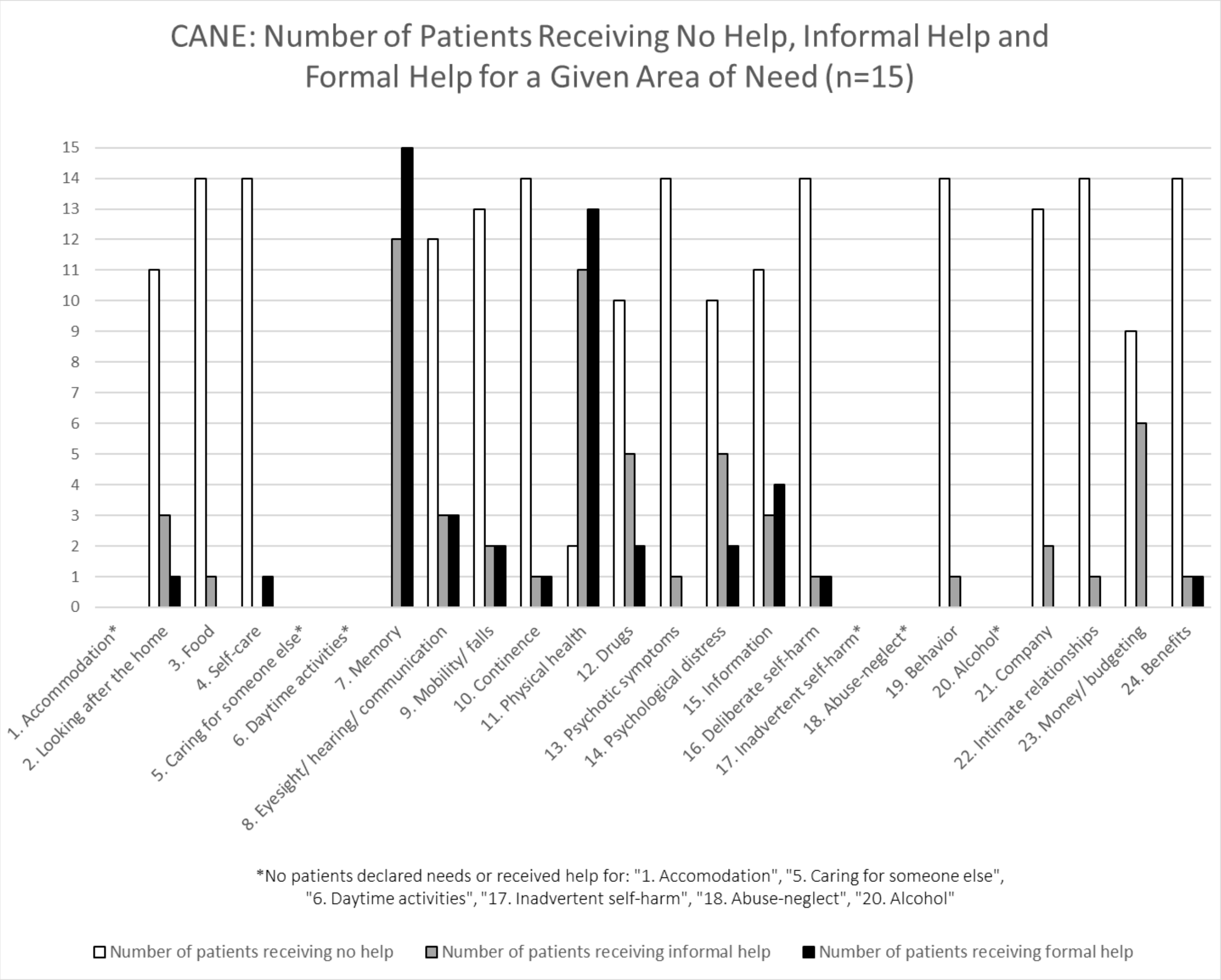


Figure 4. CANE: Number of Patients Receiving No Help, Informal Help and Formal Help for a Given Area of Need (n=15)


CANE: Number of Patients Receiving No Help, Informal Help and Formal Help for a Given Area of Need (n=15)

*No patients declared needs or received help for: "1. Accomodation", "5. Caring for someone else", "6. Daytime activities", "17. Inadvertent self-harm", "18. Abuse-neglect", "20. Alcohol"

ii. Caregiver problems and caregiver needs for services

Caregivers reported on average 2.3 moderate or serious problems (2.3, 0-7), as CNA-D revealed (Table 5). Their predominant problem was their own "physical and psychiatric health", followed by "disappointment about the patient's illness' course", want for more "information about dementia", "treatment", "services" and other problematic areas (Figure 5a-b, Appendix III). Caregivers had on average 0.8 met needs for services (0.9, 0-2) (Table 5). The chief met need is care provided by family physician (Figure 6a-b, Appendix IV). At the same time, caregivers had on average 2.4 unmet needs (3.1, 0-10) (Table 5), especially wanting "printed information material" and consulting a "social worker", but had not had the chance yet (Figure 6a-b, Appendix IV). We present both the caregiver's own answers and the researcher's assessment of the situation (Table 5; Figure 5a-b, 6a-b).

Table 5. Carers' Needs Assessment for Dementia (CNA-D): Number of problems and needs of caregivers (n=15)

Caregiver-reported number of moderate or serious problems (mean, sd, range)	Caregiver-reported number of met needs for services (mean, sd, range)	Caregiver-reported number of unmet needs for services (mean, sd, range)
2.3 (2.3, 0-7)	0.8 (0.9, 0-2)	2.4 (3.1, 0-10)
Researcher-reported number of moderate or serious problems (mean, sd, range)	Researcher-reported number of met needs for services (mean, sd, range)	Researcher-reported number of unmet needs for services (mean, sd, range)
3.3 (2.4, 0-7)	0.8 (0.9, 0-2)	2.7 (3.4, 0-10)

Figure 5a. CNA-D: Number of Moderate and Serious Problems of the Informal Caregivers as Reported by the Caregiver and the Researcher (n=15) (Part 1 of 2)

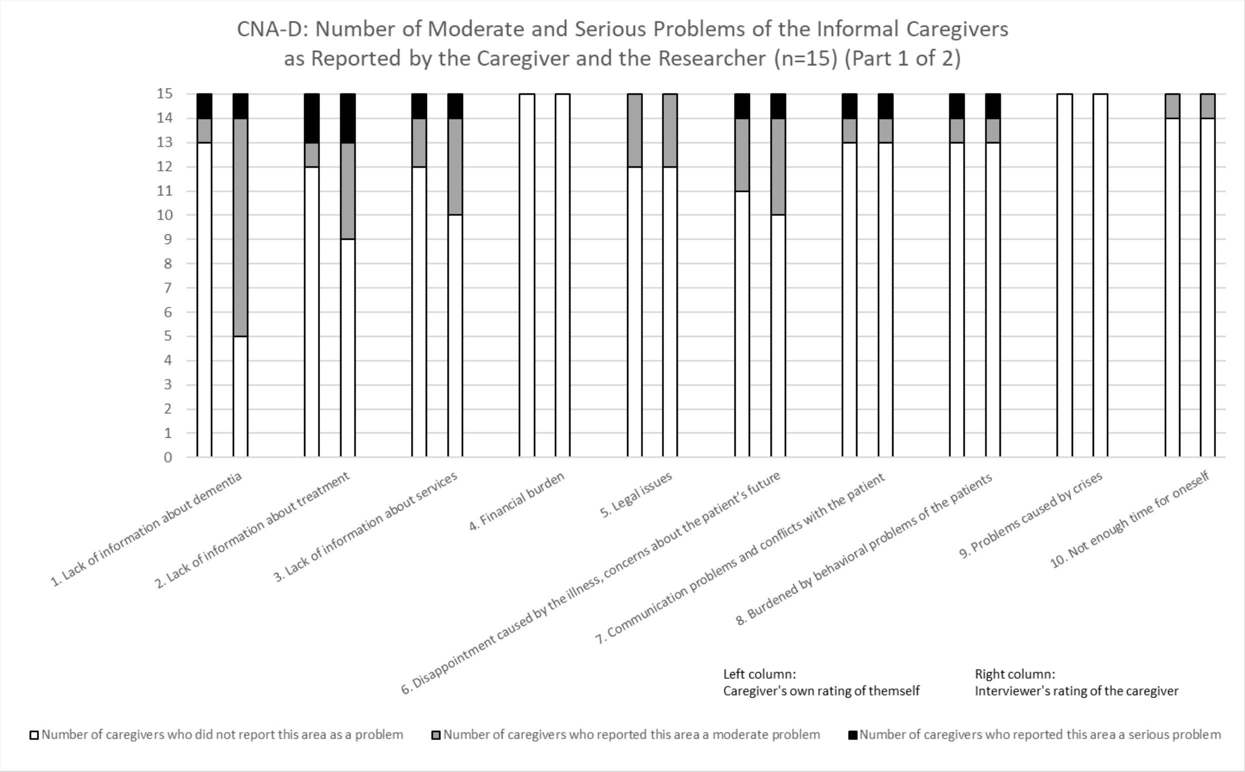


Figure 5b. CNA-D: Number of Moderate and Serious Problems of the Informal Caregivers as Reported by the Caregiver and the Researcher (n=15) (Part 2 of 2)

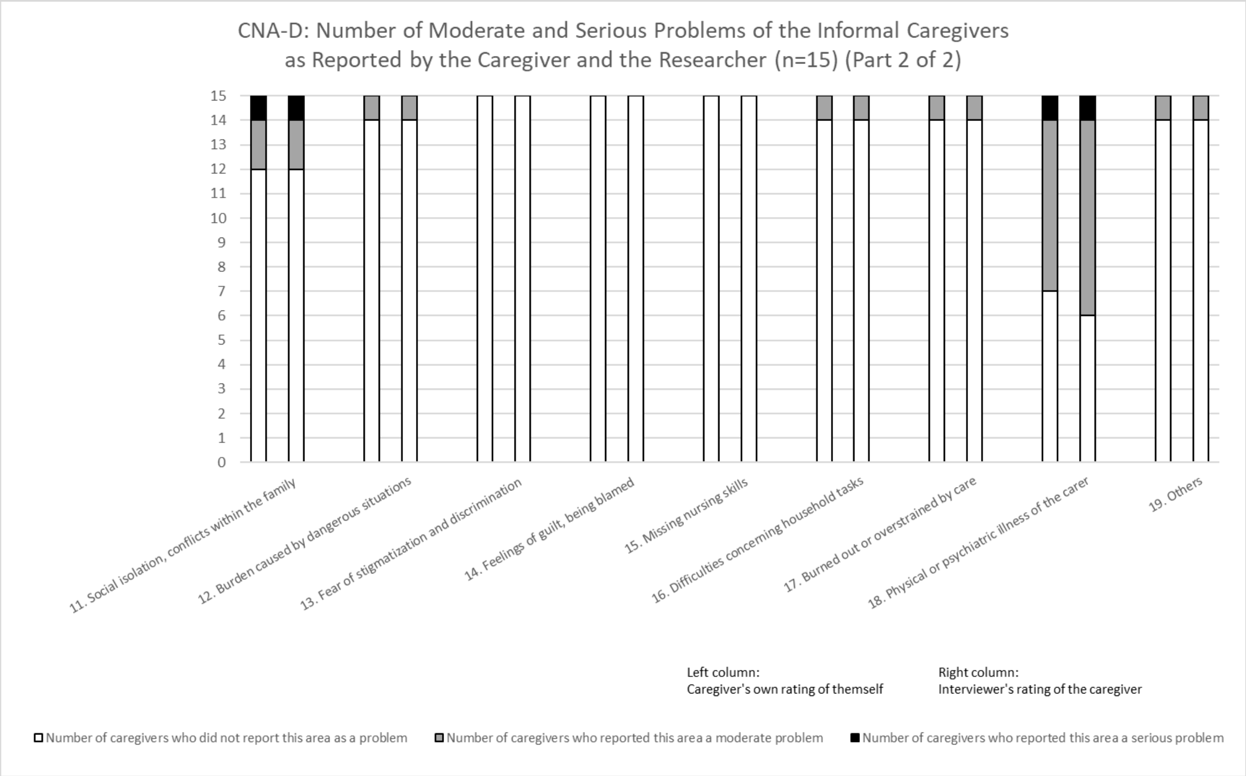


Figure 6a. CNA-D: Met and Unmet (or Partially Met) Needs of the Informal Caregivers as Reported by the Caregiver and the Researcher (n=15) (Part 1 of 2)

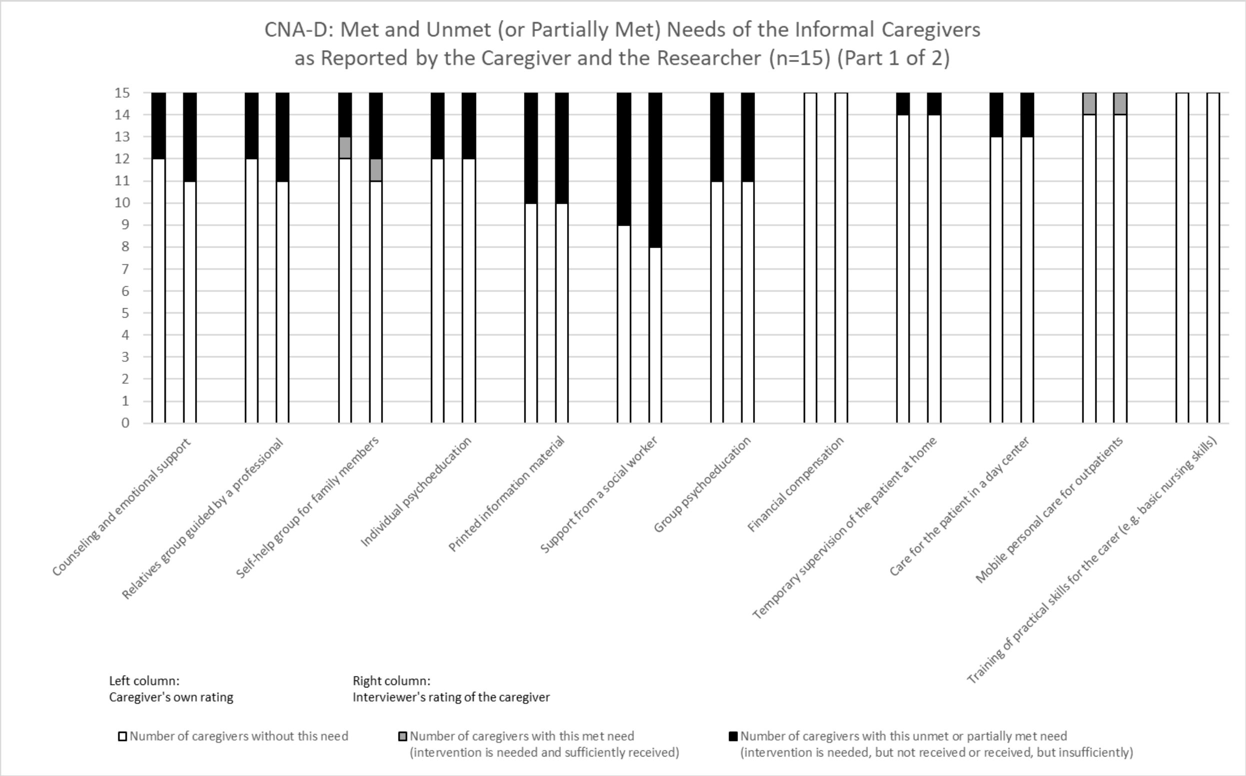
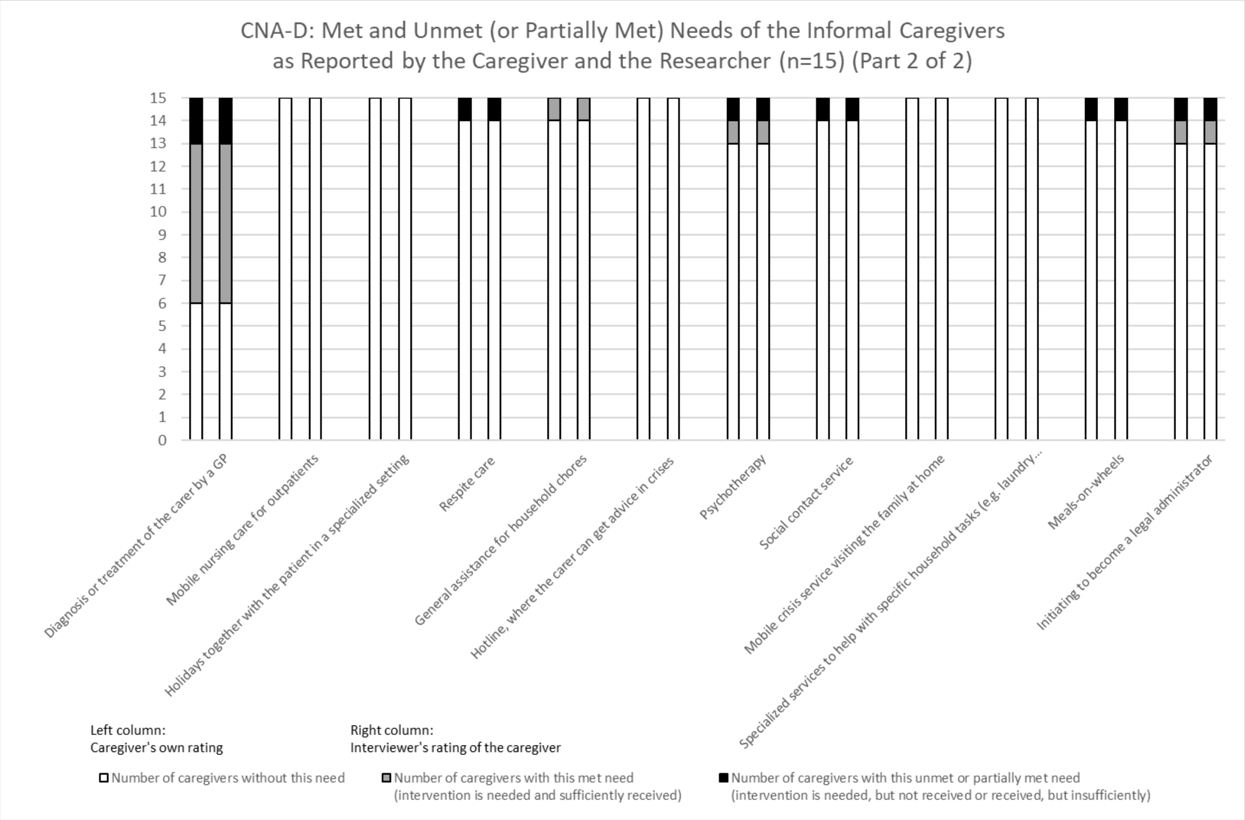


Figure 6b. CNA-D: Met and Unmet (or Partially Met) Needs of the Informal Caregivers as Reported by the Caregiver and the Researcher (n=15) (Part 2 of 2)



c. Answering Research Question 3: Sociodemographic, Ethnocultural, Memory and Health Characteristics of Canadian Born vs. Foreign Born Patients and Caregivers

i. Characteristics of Canadian born vs. foreign born patients

On average, foreign born patients were older, but had a similar sex distribution to their Canadian born peers (Table 6a). Canadian born and foreign born patients were similarly educated, were almost all retired and were almost always the spouse or the partner of their informal caregiver.

The five Canadian born patients each reported a different ethnic origin: “Caucasian”, “French,”, “French Canadian”, “Jewish” and “Quebecer” (Table 6a). The 10 foreign born patients reported eight different ethnic origins, comprising of one “Caucasian”, one “Filipino”, one “French”, one “Haitian”, one “Italian”, one “Jamaican”, one “South African”, with the remainder three patients answering “Jewish”. None of the Canadian born patients self-identified as a visible minority, while three foreign born patients did. More foreign born patients spoke a foreign language natively, and they were more likely to know just one of the two official languages of Canada. Our study’s Canadian born and foreign born patients appeared to hold similar spiritual beliefs.

Table 6a. Sociodemographic and ethnocultural characteristics of Canadian born and foreign born patients (Canadian n=5, foreign n=10)

	Canadian born	Foreign born
Age (mean, sd, range)	74.8 (12.3, 61-91)	77.4 (7.9, 61-90)
Sex, male (number, %)	3 (60.0%)	7 (70.0%)
Sex, female (number, %)	2 (40.0%)	3 (30.0%)
Highest level of education received		
Below high school (number, %)	0 (0.0%)	3 (30.0%)
High school or apprenticeship (number, %)	4 (80.0%)	4 (40.0%)
College, CEGEP, university and above (number, %)	1 (20.0%)	3 (30.0%)
Labor force status and work activity		
Retired (number, %)	5 (100.0%)	9 (90.0%)
Working part-time (number, %)	0 (0.0%)	0 (0.0%)
Working full-time (number, %)	0 (0.0%)	1 (10.0%)
Relationship between patient and caregiver		
Couple (number, %)	5 (100.0%)	9 (90.0%)
Parent-child (number, %)	0 (0.0%)	1 (10.0%)
Other (number, %)	0 (0.0%)	0 (0.0%)
Ethnocultural characteristics		
Ethnic origins	“Caucasian”=1 “French”=1 “French Canadian”=1 “Jewish”=1 “Quebecer”=1	“Caucasian”=1 “Filipino”=1 “French”=1 “Haitian”=1 “Italian”=1 “Jamaican”=1 “Jewish”=3 “South African”=1
Visible minority (number, %)	0 (0.0%)	3 (30.0%)
Knowledge of official languages of Canada (French and English) and other languages		
No knowledge of official language (number, %)	0 (0.0%)	0 (0.0%)
Unilingual, speaks one official language (number, %)	2 (40.0%)	6 (60.0%)
speaks only French (number, %)	2 (40.0%)	2 (20.0%)
speaks only English (number, %)	0 (0.0%)	4 (40.0%)
Bilingual, speaks French and English (number, %)	3 (60.0%)	4 (40.0%)
Speaks foreign language(s) natively (number, %)	1 (20.0%)	5 (50.0%)
Spiritual beliefs		
Agnosticism or atheism (number, %)	2 (40.0%)	3 (30.0%)
Christianism (number, %)	2 (40.0%)	4 (40.0%)
Judaism (number, %)	1 (20.0%)	3 (30.0%)

Foreign born patients had been suffering memory issues for longer, scored lower on MMSE and MoCA, and were more often prescribed a cholinesterase inhibitor (Table 6b). Caregivers reported that foreign born patients experienced more behavioral symptoms compared to their Canadian born counterparts, as measured by NPI.

At the same time, foreign born patients suffered from a smaller number of comorbid conditions and were prescribed less medications of all kinds (Table 6b). However, foreign patients had a lower quality of life, as measured by QOL-AD.

Table 6b. Memory and health characteristics of Canadian born and foreign born patients (Canadian n=5, foreign n=10)

Patient’s memory issues		
Self-reported onset in years (means, sd, range)	3.0 (1.2, 2-5)	3.1 (2.3, 1-9)
MMSE (mean, sd, range)	28.2 (1.1, 27-30)	26.4 (2.7, 21-30)
MoCA (mean, sd, range)	25.6 (1.5, 24-27)	21.2 (3.1, 15-25)
Prescribed cholinesterase inhibitor (number, %)	1 (20.0%)	4 (40.0%)
NPI		
12 item NPI score (mean, sd, range)	4.8 (8.6, 0-20)	6.9 (7.5, 0-20)
Patient’s health		
Number of comorbidities (mean, sd, range)	5.2 (2.0, 2-7)	4.1 (2.4, 1-8)
Number of active medications (mean, sd, range)	10.0 (2.0, 7-12)	8.1 (2.2, 5-11)
QOL-AD		
Scored by patient (mean, sd, range)	42.2 (2.9, 39-46)	37.10 (5.1, 28-43)
Scored by caregiver (mean, sd, range)	37.0 (10.4, 20-48)	34.9 (7.5, 19-47)

ii. Characteristics of Canadian born vs. foreign born caregivers

On average, foreign born caregivers were younger and had a similar female-male distribution compared with their Canadian peers (Table 7). A higher proportion of Canadian born caregivers received post-secondary education. The great majority of foreign born and Canadian born caregivers alike were retired, and again, all caregivers except one foreign born caregiver was the spouse or the partner of the patient.

The six Canadian born caregivers reported five distinct ethnic origins, with one “Albanian-Canadian”, two “Canadians,” one “French”, one “Italian-Canadian” and one “Quebecer” (Table 7). The nine foreign born caregivers reported seven distinct ethnic origins, with one “Afro American”, one “Caucasian”, one “Filipino”, one “French”, one “Italian” and one “Jamaican”, with the remainder three caregivers answering “Jewish”. None of the Canadian born caregivers self-identified as a visible minority, while three foreign caregivers did (33.3%). More foreign born caregivers spoke a foreign language natively, and they were more likely to know just one of the two official languages of Canada compared to their Canadian born counterparts. While our study’s Canadian born caregivers’ spiritual beliefs were evenly distributed between three Christians (50.0%) and three agnostics or atheists (50.0%), their foreign born peers had a slight Christian majority of five caregivers (55.6%), followed by three Jewish caregivers (33.3%) and just one caregiver who was agnostic or atheist (1.1%).

Compared to their Canadian born counterparts, foreign born caregivers reported higher distress associated with the patient's behavioral symptoms (Table 7).

Table 7. Characteristics of Canadian born and foreign born caregivers (Canadian n=6, foreign n=9)

	Canadian born	Foreign born
Age (mean, sd, range)	75.5 (13.3, 1-5)	70.2 (12.3, 41-83)
Sex, male (number, %)	1 (16.7%)	2 (22.2%)
Sex, female (number, %)	5 (83.3%)	7 (77.8%)
Highest level of education received		
Below high school (number, %)	1 (16.7%)	3 (33.3%)
High school or apprenticeship (number, %)	1 (16.7%)	3 (33.3%)
College, CEGEP, university and above (number, %)	4 (66.7%)	3 (33.3%)
Labor force status and work activity		
Retired (number, %)	4 (66.7%)	7 (77.8%%)
Working part-time (number, %)	0 (0.0%)	1 (11.1%)
Working full-time (number, %)	2 (33.3%)	1 (11.1%)
Relationship between patient and caregiver		
Couple (number, %)	6 (100.0%)	8 (88.9%)
Parent-child (number, %)	0 (0.0%)	1 (11.1%)
Other (number, %)	0 (0.0%)	0 (0.0%)
Ethnocultural characteristics		
Ethnic origins	"Albanian-Canadian"=1 "Canadian"=2 "French"=1 "Italian-Canadian"=1 "Quebecer"=1	"Afro American"=1 "Caucasian"=1 "Filipino"=1 "French"=1 "Italian"=1 "Jamaican"=1 "Jewish"=3
Visible minority (number, %)	0 (0.0%)	3 (33.3%)
Knowledge of official languages of Canada (French and English) and other languages		
No knowledge of official language (number, %)	0 (0.0%)	0 (0.0%)
Unilingual, speaks one official language (number, %)	2 (33.3%)	6 (66.7%)
speaks only French (number, %)	0 (0.0%)	3 (33.3%)
speaks only English (number, %)	2 (33.3%)	3 (33.3%)
Bilingual, speaks French and English (number, %)	4 (66.7%)	3 (33.3%)
Speaks foreign language(s) natively (number, %)	1 (16.7%)	6 (66.7%)
Spiritual beliefs		
Agnostic or atheist (number, %)	3 (50.0%)	1 (11.1%)
Christian (number, %)	3 (50.0%)	5 (55.6%)
Jewish (number, %)	0 (0.0%)	3 (33.3%)
NPI		
12 item caregiver distress score (mean, sd, range)	0.8 (1.4, 0-3)	5.3 (6.3, 0-20)

d. Answering Research Question 4: Needs and Problems of Canadian Born vs. Foreign Born Patients and Caregivers

i. Needs of Canadian born vs. foreign born patients

Foreign born patients reported more needs (Table 8) and exhibited a different profile of needs compared to Canadian born patients (Figure 7a-c, 8a-c). Of course, the groups shared some similarities; indeed, the most prevalent concerns for both groups were “memory”, “physical health” and “money/budgeting” (Figure 7a-c, 8a-c). However, important differences existed too: only foreign born patients reported needs in “eyesight, hearing, communication”, “mobility/falls”, “looking after the home” and “company” (Figure 7a-c, 8a-c).

Table 8. Needs of Canadian born and foreign born patients (Canadian n=5, foreign n=10)

CANE	Canadian born	Foreign born
Patient-reported met needs (mean, sd, range)	3.2 (1.1, 2-5)	4.0 (2.1, 2-8)
Patient-reported unmet needs (mean, sd, range)	0.6 (0.9, 0-2)	0.5 (1.3, 0-4)
Patient-reported total needs (mean, sd, range)	3.8 (1.3, 2-5)	4.5 (2.0, 2-8)

Figure 7a. CANE: The Canadian Born Patients' Met and Unmet Needs (n=5) (Part 1 of 3)

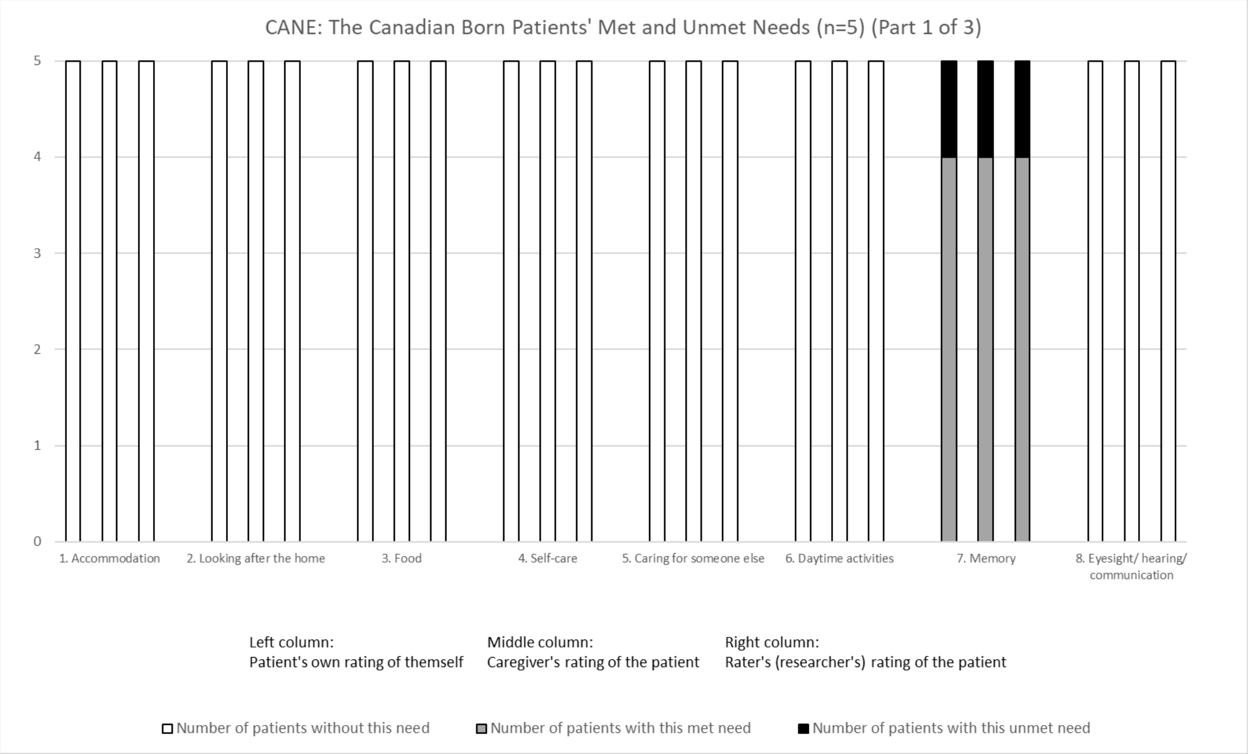


Figure 7b. CANE: The Canadian Born Patients' Met and Unmet Needs (n=5) (Part 2 of 3)

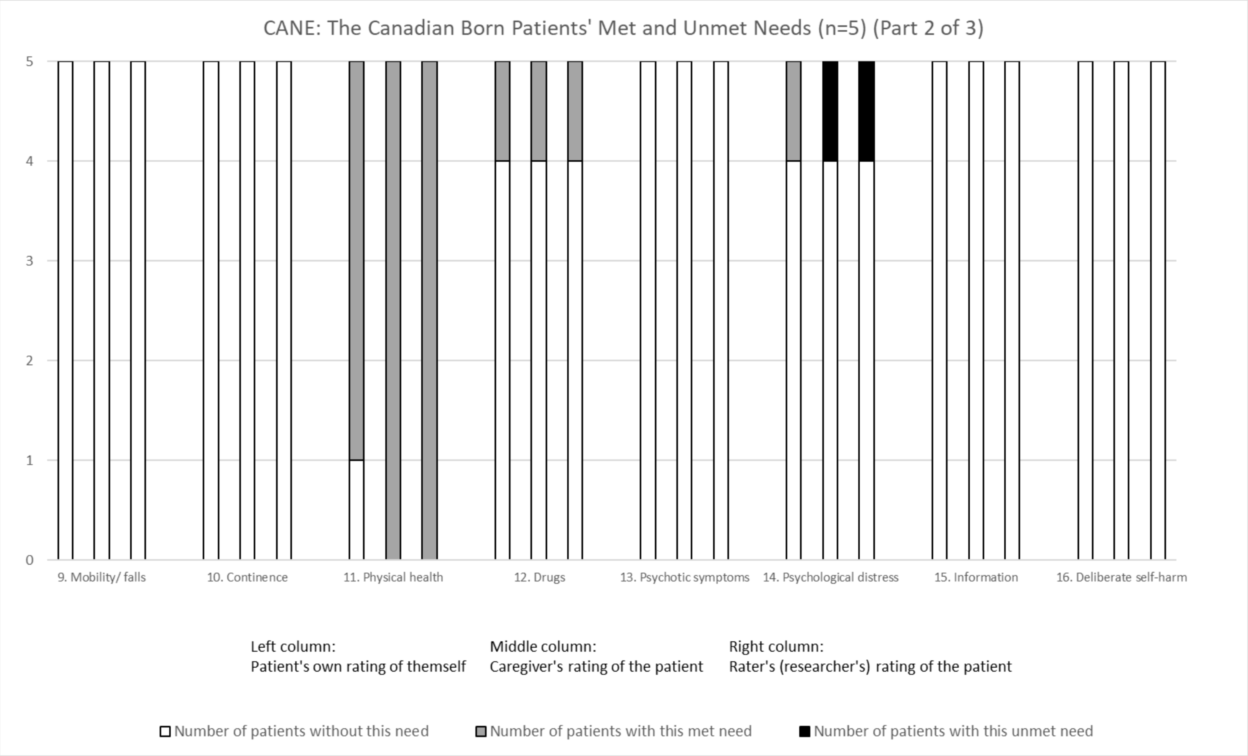


Figure 7c. CANE: The Canadian Born Patients' Met and Unmet Needs (n=5) (Part 3 of 3)

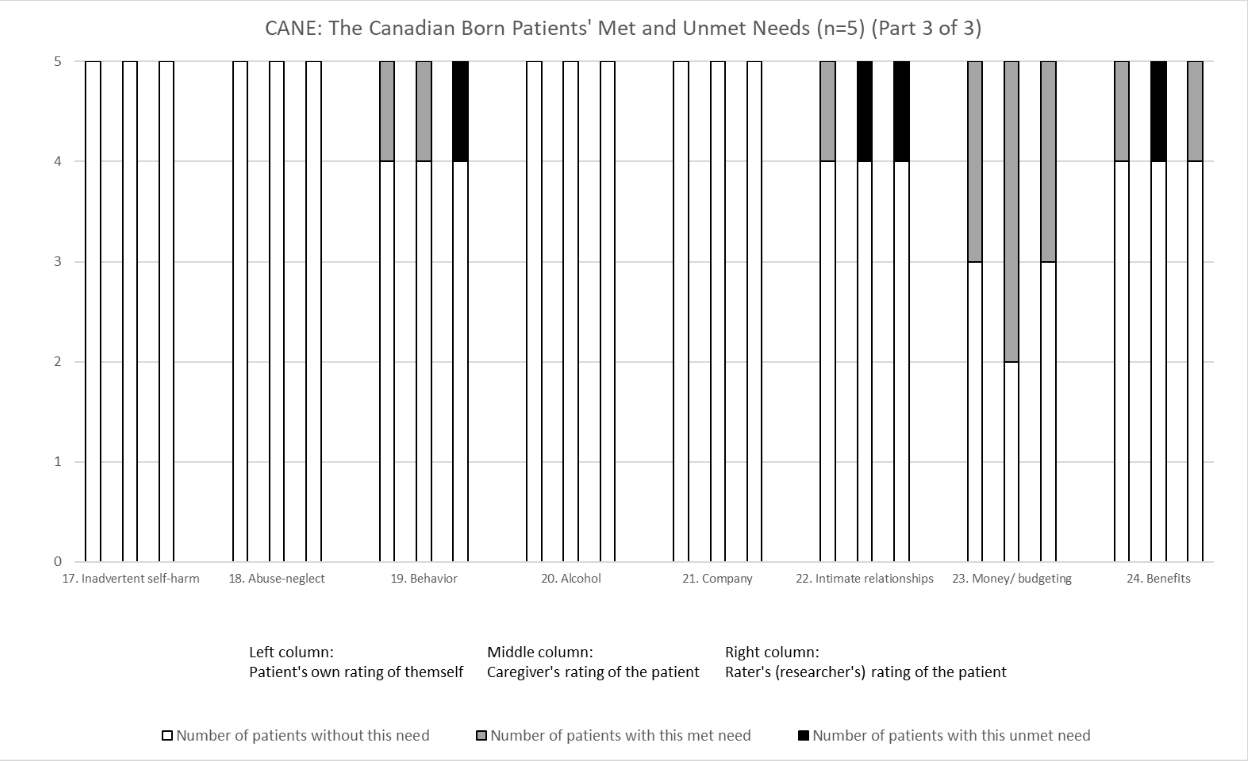


Figure 8a. CANE: The Foreign Born Patients' Met and Unmet Needs (n=10) (Part 1 of 3)

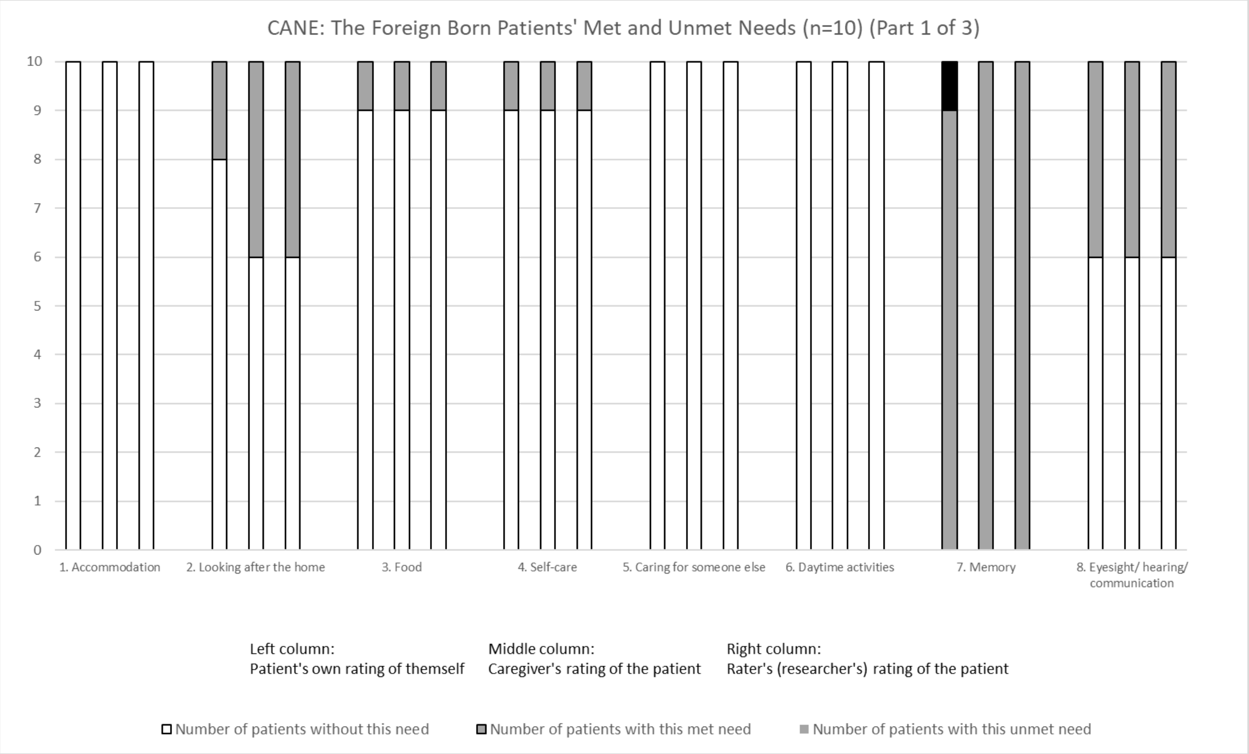


Figure 8b. CANE: The Foreign Born Patients' Met and Unmet Needs (n=10) (Part 2 of 3)

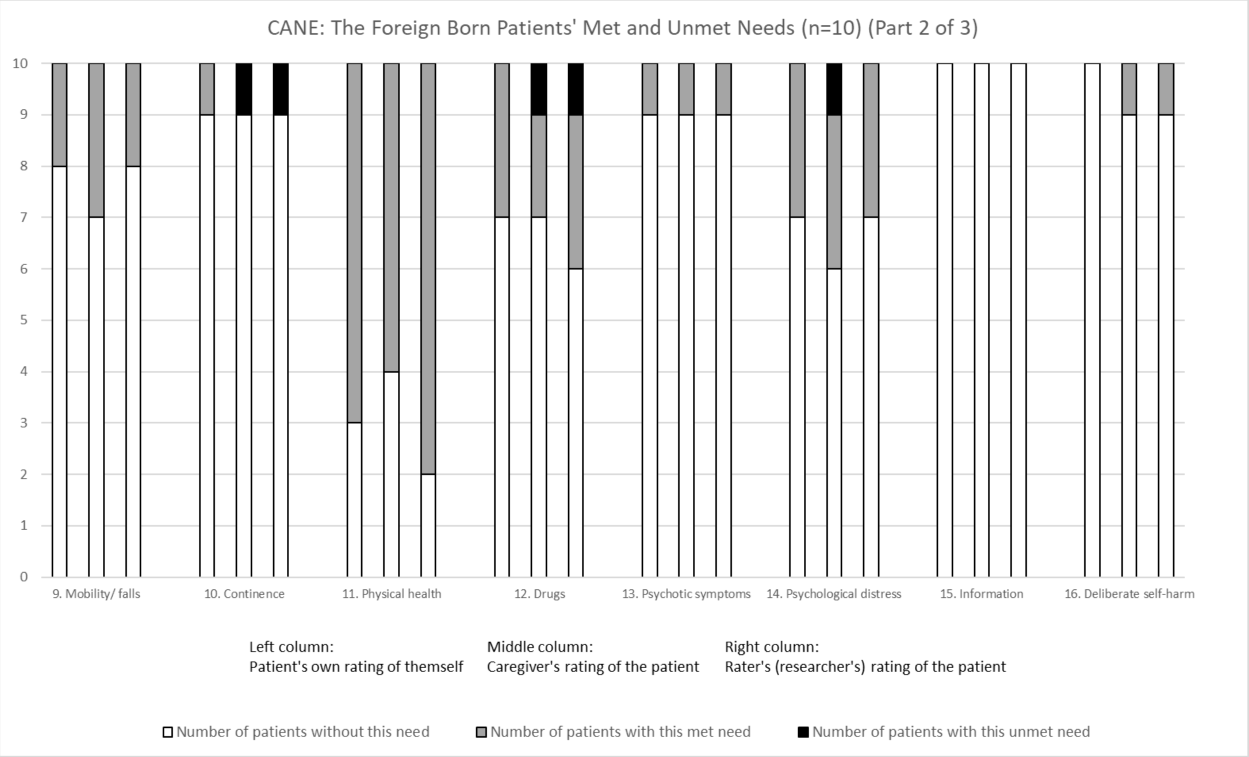
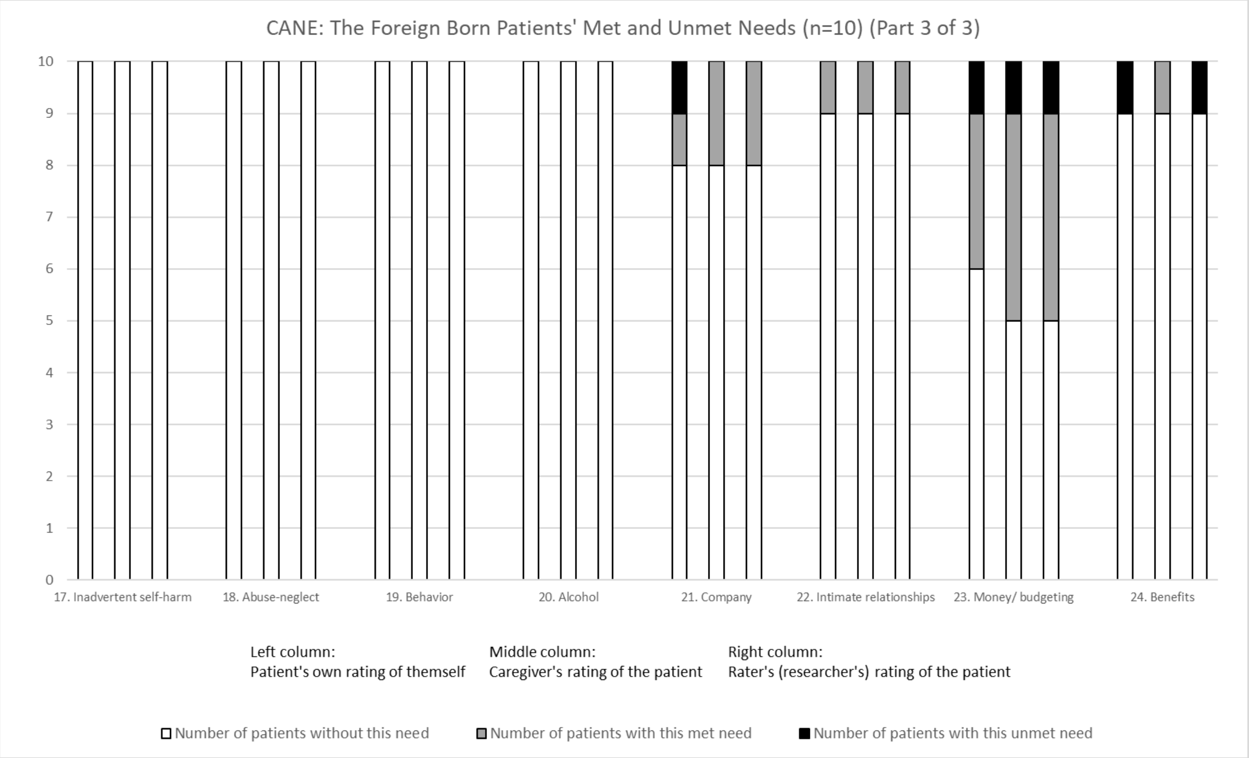


Figure 8c. CANE: The Foreign Born Patients' Met and Unmet Needs (n=10) (Part 3 of 3)



ii. Problems and needs of Canadian born vs. foreign born caregivers

The foreign born caregivers reported having more problems, more met needs and more unmet needs (Table 9).

Table 9. Problems and needs of Canadian born and foreign born caregivers (Canadian n=6, foreign n=9)

CNA-D	Canadian born	Foreign born
Number of moderate or serious problems (mean, sd, range)	1.5 (2.7, 0-5)	2.9 (2.4, 0-7)
Met needs (mean, sd, range)	0.7 (0.9, 0-2)	0.9 (0.8, 0-2)
Unmet needs (mean, sd, range)	1.8 (3.0, 0-7)	2.8 (3.2, 0-10)

Though the primary problem to both groups of caregivers was their physical and psychiatric health, there were important differences in the problems of foreign born and Canadian born caregivers (Figure 9a-b, 10a-b). For instance, foreign born caregivers wanted more “information about dementia” and “about treatment”, while their Canadian born peers wanted more “information about treatment” and “about services” (Figure 9a-b, 10a-b). Only foreign born caregivers complained of “legal issues”, “communication problems and conflicts with the patient”, “burden by behavioral problems of the patient” and “social isolation and conflicts within the family” (Figure 9a-b, 10a-b).

Figure 9a. CNA-D: The Canadian Born Caregivers' Problems (n=6) (Part 1 of 2)

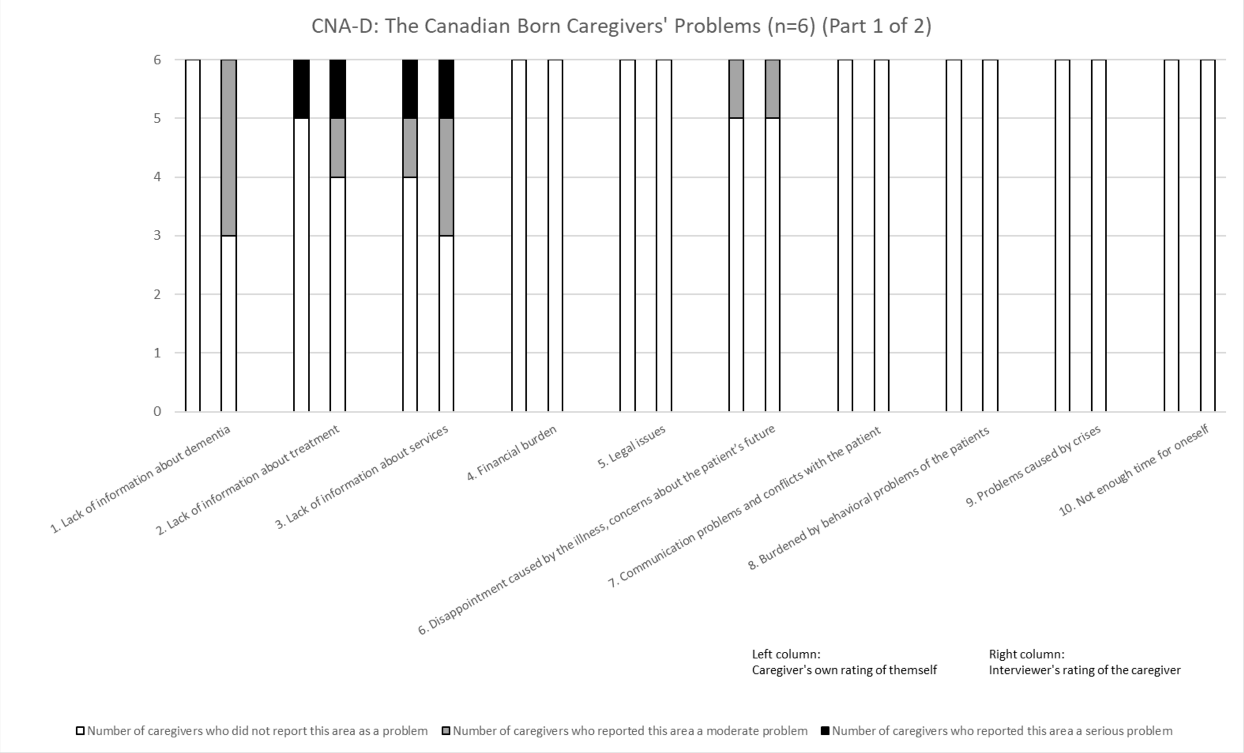


Figure 9b. CNA-D: The Canadian Born Caregivers' Problems (n=6) (Part 2 of 2)

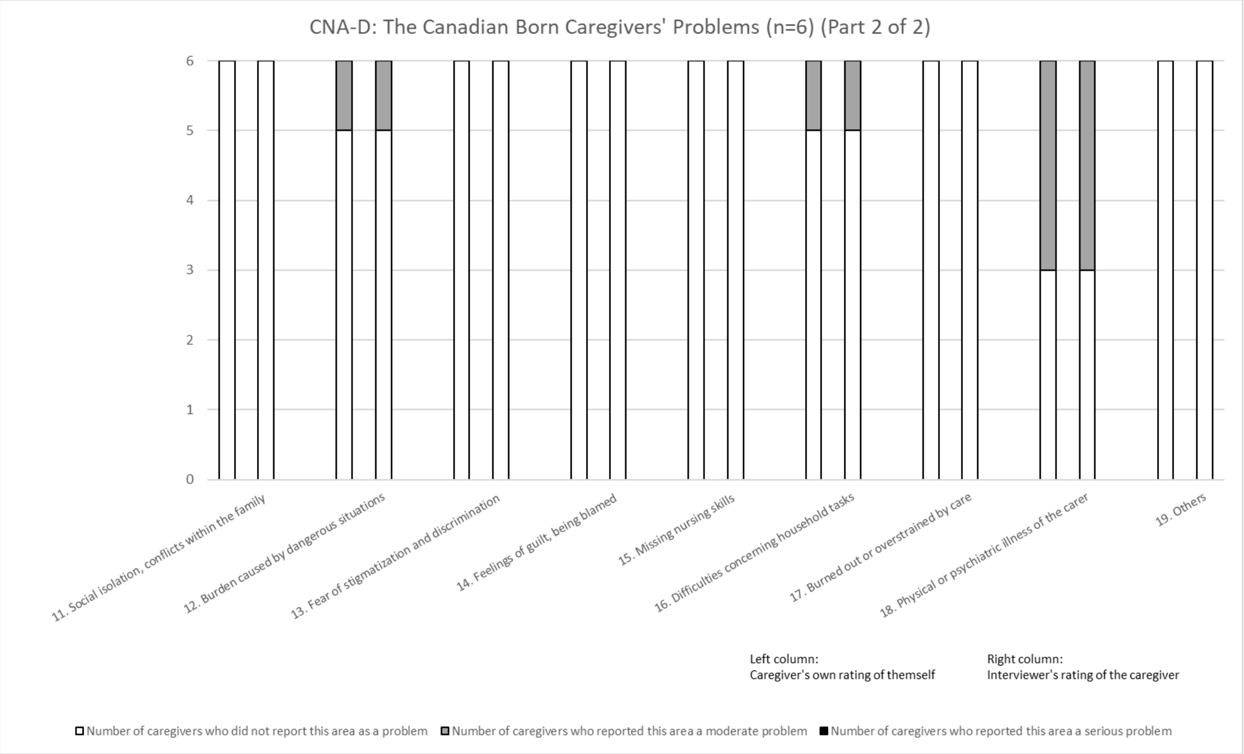


Figure 10a. CNA-D: The Foreign Born Caregivers' Problems (n=9) (Part 1 of 2)

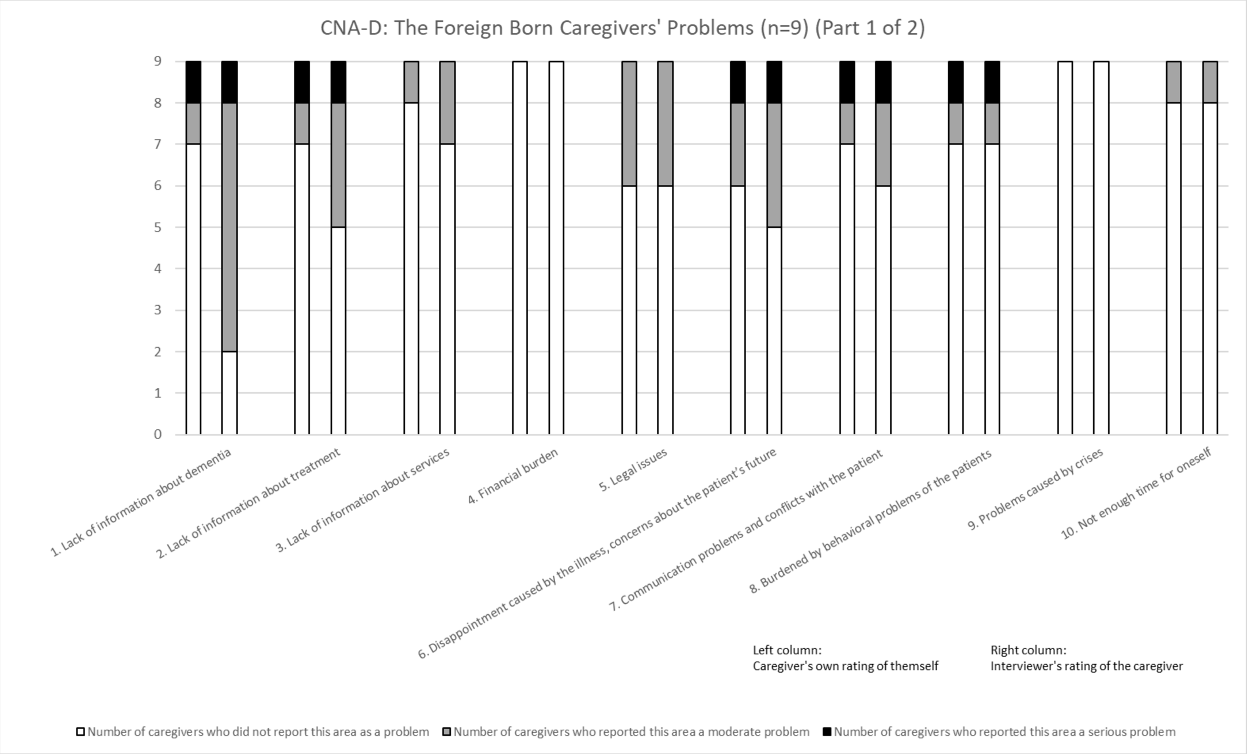
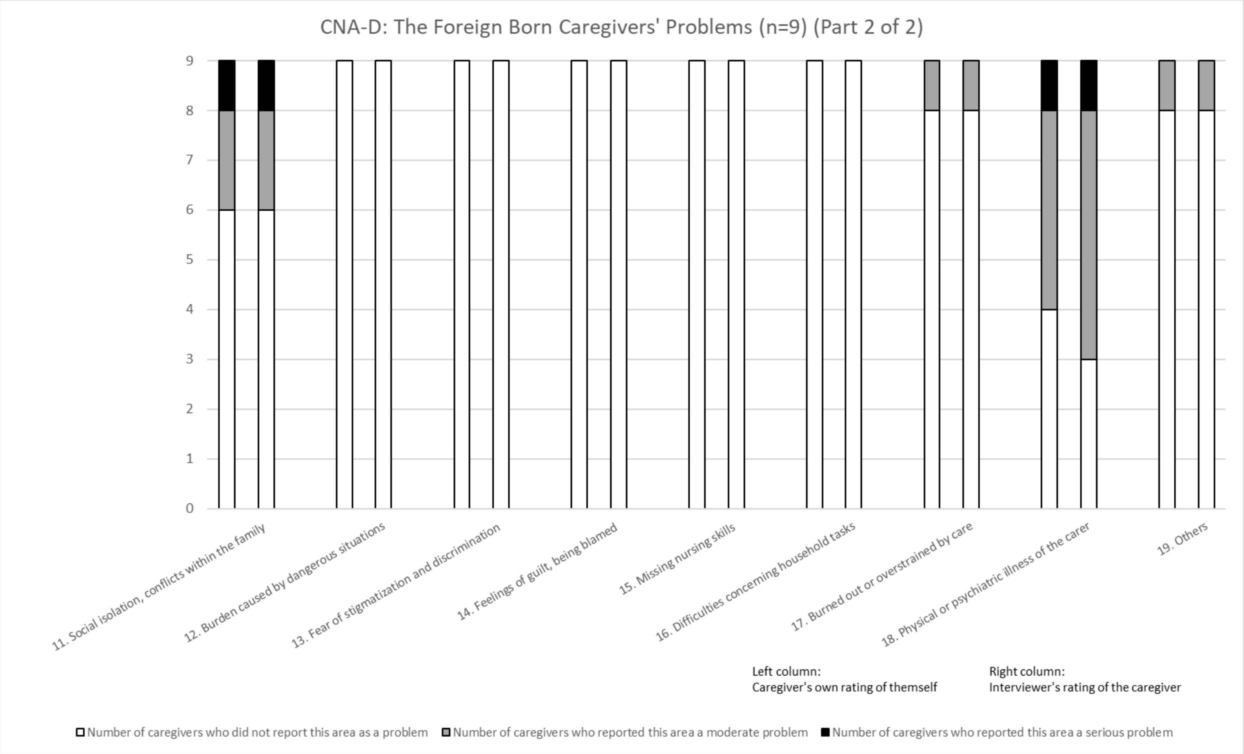


Figure 10b. CNA-D: The Foreign Born Caregivers' Problems (n=9) (Part 2 of 2)



Likewise, there were differences in the needs for services of caregivers born inside vs. outside of Canada (Figure 11a-b, 12a-b). Foreign born caregivers did not receive but showed interest in "temporary supervision of the patient at home", "care for the patient in a day center", "respite care", "self-help group for family members" and help "initiating to become a legal administrator", all of which their Canadian born peers did not express a need for (Figure 11a-b, 12a-b).

Figure 11a. CNA-D: The Canadian Born Caregivers' Needs for Services (n=6) (Part 1 of 2)

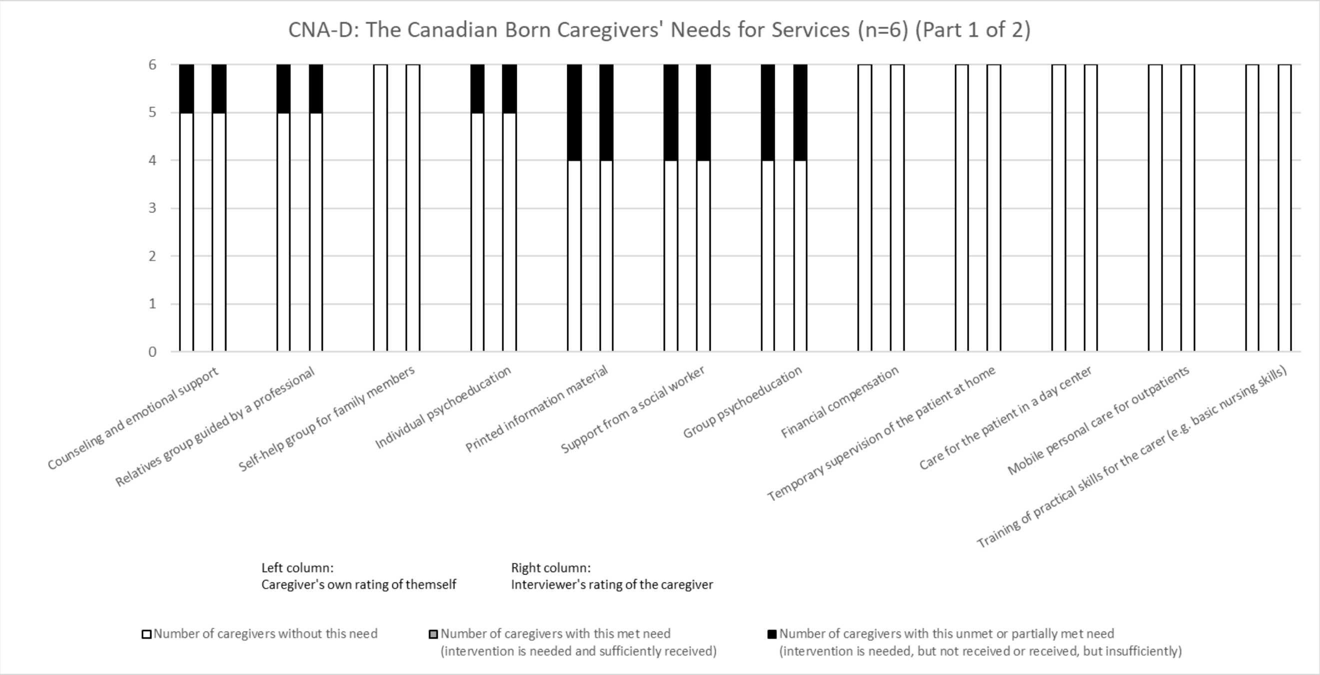


Figure 11b. CNA-D: The Canadian Born Caregivers' Needs for Services (n=6) (Part 2 of 2)

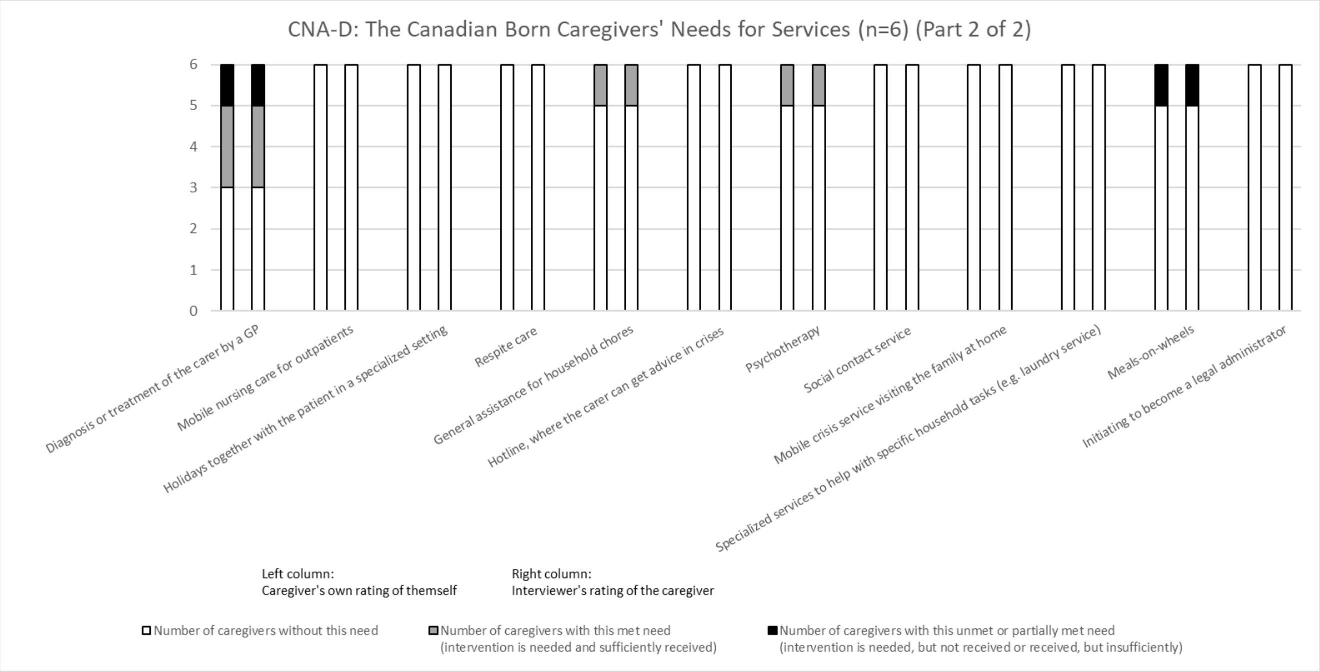


Figure 12a. CNA-D: The Foreign Born Caregivers' Needs for Services (n=9) (Part 1 of 2)

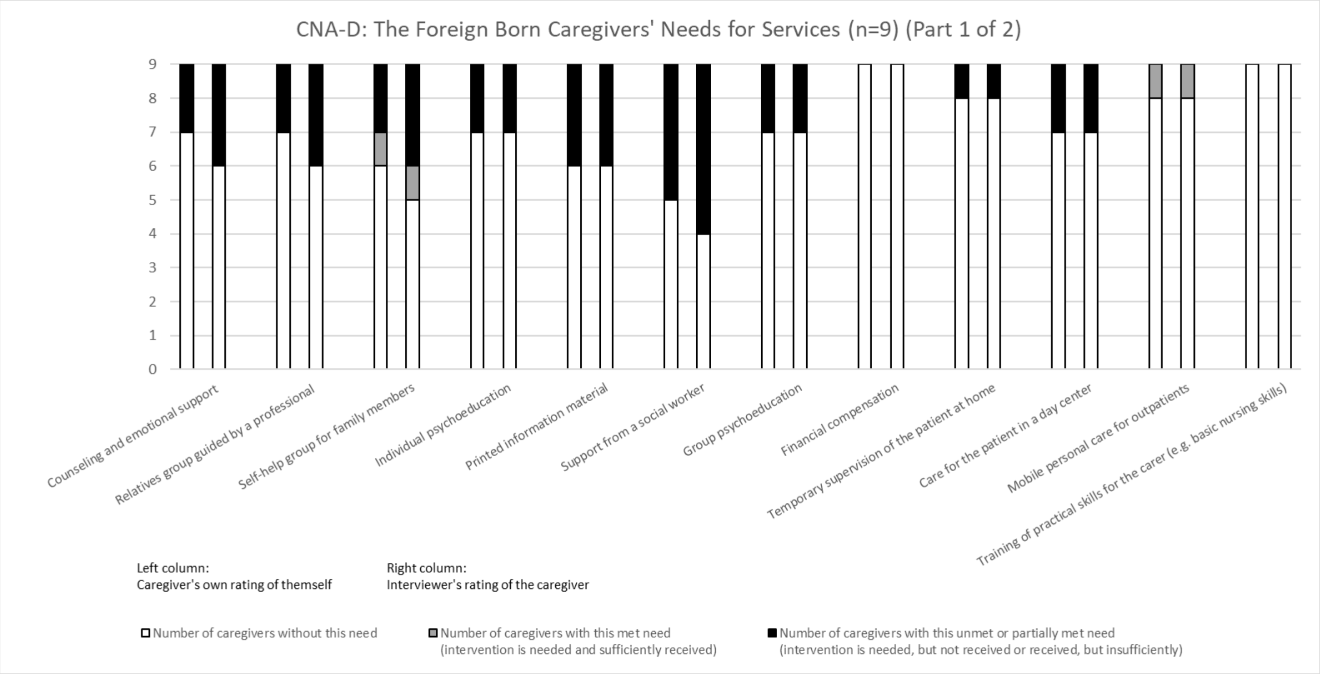
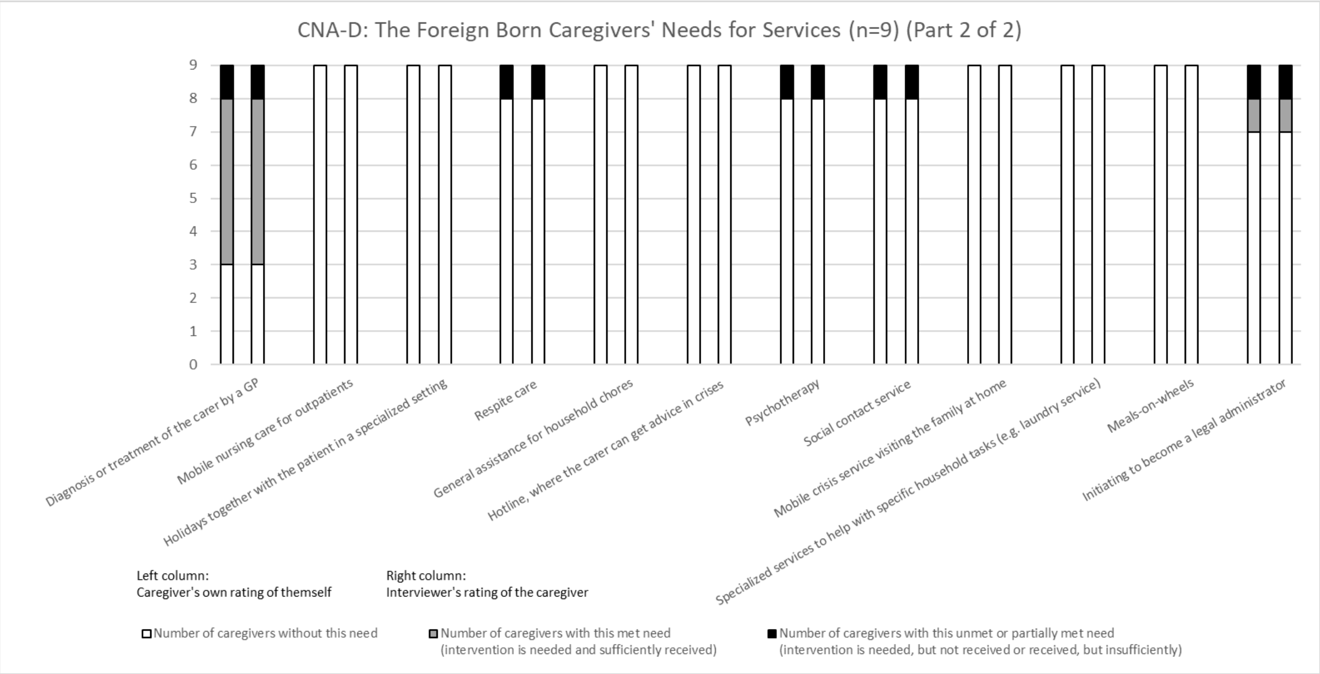


Figure 12b. CNA-D: The Foreign Born Caregivers' Needs for Services (n=9) (Part 2 of 2)



Chapter 5: Discussion, Limitations, Conclusions and Future Directions

a. Discussion

i. Summary of results

Although the topics of dementia, case management and culture have been investigated and discussed extensively in the existing literature, our pilot study is innovative because it took into account all three concepts, in a context where all three were present and relevant.

The 15 patients were on average 76.5 years old (sd: 9.2, range: 61-91), of which 10 were men, still in the early stages of cognitive decline with a mean MoCA of 22.7 (3.4, 15-27). Patients reported "memory", "physical health", "money/budgeting" as common needs, and received both informal and formal help to meet most needs. The 15 caregivers were aged 72.3 years old (12.5, 41-90), with 12 women. They reported "physical or psychiatric illness" and "lack of information about dementia", "about treatment" and "about services" as common problems. They received adequate "diagnosis or treatment" from the family physician, but their needs for "support from a social worker", "printed information material" and other services were not met.

Compared to their five Canadian born counterparts, the 10 foreign born patients had more needs (and different needs) and a lower quality of life. This may be explained by their older age, longer onset of memory symptoms, worse cognition and more behavioral symptoms. The nine foreign born caregivers were younger than their six Canadian born peers, but reported more stress associated with their patient's behavioral symptoms, more problems (and different problems) and more needs (and different needs) for services.

ii. On research question 1: sociodemographic characteristics: comparison to the target population and the national data

The patients who participated in our study were different in age and sex compared to the Herzl clinic's dementia patient population as well as the closest comparable national averages.

To begin, we compared our study sample with the study site's patient population from which we recruited. Compared to all 161 patients who had a clinical visit for their memory, the 15 patients who ultimately participated in our study were younger on average and more often a man. We observe the same trends if instead we compared the study participants to all potentially eligible patients of the Herzl: we enrolled younger patients and proportionally more male patients. Indeed, there may have been selection bias. Older patients may be sicker and more frail, and they may more easily decline to participate or not answer the phone. However, we cannot clearly explain why men participated more than women.

We can draw similar conclusions when comparing our study sample and study site with the national context of persons living with dementia. Indeed, while the Herzl clinic's dementia patient population resembled the national data in its age and sex distributions, our study sample was noticeably different in these aspects.

In Canada, there was an estimated 109,500 people aged 45 or older living in private households who received a diagnosis of dementia [131]. Prevalence increased with age: while 13,200 (about 12.0%) were aged 45-64, 36,900 (about 33.7%) were aged 65-79 and 59,300 (about 54.2%) were aged 80 and older [131]. About 53.0% of these patients were women [131, 132].

Our study site had 135 potential community-dwelling dementia patients (from the initial 161 patients with known memory complaints at the Herzl, we could remove the "deceased", those "placed in home" and those found to have "no memory issues" to form a hypothetical population). The age distribution of this hypothetical population approximated the Canadian statistics: 8.9% are aged 45-64, 34.1% are aged 65-70 and 57.0% are aged 80 and older. The sex distribution was 50.4% female. We observe that our study site's patient population was actually similar to the national average.

At the same time, we observe that our sample was relatively young and proportionally more male in comparison to the national context of persons living with dementia. Indeed, compared to the Canadian distribution, our sample was composed of two patients aged 45-64 (13.3%), eight patients aged 65-79 (53.3%) and five patients aged 80 and older (33.3%). 10 patients who participated (66.7%) were male. While the study site's patient population from which we recruited was comparable in age and sex to the national average of community-dwelling dementia patients, our study participants were markedly different in these characteristics; we may be observing selection bias in our study.

In Canada, among people aged 45 to 75 with dementia, 99% were not working [131]. Similarly in our study, nearly all but one patient out of 15 were retired.

In Canada, the informal caregiver of a dementia patient was a spouse in 46% of cases, an adult child in 44% of cases, and other relatives, friends and neighbors in 9% of cases [131]. In our study, 14 pairs (93.3%) of patients and caregivers were couples, while only one pair (6.7%) was composed of a parent and a child. We may be observing a different instance of selection bias; adult child caregivers of dementia patients tend to be more active in the workforce, may need to care for their own families or may have other responsibilities that occupy their time and disallow them from participating in research. That said, we provided the most flexibility in time and place possible to patients and caregivers when recruiting. Also, informal caregivers who participate in the workforce did find representation in our study, as four of our 15 caregivers were still working: one on a part-time basis and three full-time.

iii. On research question 1: ethnocultural characteristics: comparison to the local diversity

The dementia patients who participated in our study, as well as their caregivers, were ethnoculturally diverse.

Immigrants and non-permanent residents made up about a quarter of Montreal's population and about half of the borough of Côte-des-Neiges–Notre-Dame-de-Grâce where our study site is located [22, 23]. Our sample exceeded these figures; about two thirds of study participants were born and raised outside of Canada, with the average age at immigration being in the mid 30s. Furthermore, our patients and caregivers came from a great variety of countries with markedly different cultures, from Canada and France, to Italy and Morocco, to the Philippines and South Africa to name just half of them. They reported equally varied ethnic origins. Our sample also surpassed the city's and the borough's population in linguistic richness [22, 23], with half the study participants speaking a foreign language as a mother tongue.

That said, just one in 5 study participants self-identified as a visible minority. It is comparable to the Montreal census [22], while in Côte-des-Neiges–Notre-Dame-de-Grâce, the proportion of the population self-identifying as a visible minority was decidedly higher at 45.81% [23].

Our sample, then, was ethnoculturally rich and diverse compared to the city's and the borough's populations. However, we cannot say that our sample was representative of the city's or the clinic's dementia patient population in its cultural composition because we cannot definitely exclude the possibility of selection bias with regard to these characteristics.

iv. On research question 1: behavioral manifestations: interpretation using the literature

On average, caregivers of our study rated the patients' behavioral symptoms (since the onset of memory issues) at 6.2 (7.7, 0-20) on the NPI. However, we take note of the great standard deviation and range. Indeed, four patients did not experience any such symptoms, five patients were symptomatic in only one domain, while only a minority of patients, the remainder six, was more neuropsychiatrically affected and drove the average NPI upwards.

There was also great heterogeneity in caregiver distress associated with the patient's behavioral symptoms, measured by NPI to a mean of 3.5 (5.3, 0-20). Again we take note of the standard deviation and range. Indeed, six caregivers had reported no distress, eight caregivers scored between 1 and 9 inclusively, and the remaining one caregiver scored 20. The outlier affected the mean score noticeably.

Our patients' commonest symptoms were "depression" and "sleep and nighttime behavior disorders". This was in part corroborated by our data on patient needs, of which "psychological distress" was found to be prevalent in our patients.

Because of our small sample size and the great heterogeneity of NPI results within (the great standard deviation and range), it is difficult to compare to existing studies which also used NPI. In addition, past studies were usually concerned with patients suffering more advanced cognitive decline, with markedly lower MMSE scores and not necessarily living in the community [93, 133]. Though the study populations were not comparable to ours, the studies offered insight in analyzing and interpreting more severe behavioral manifestations, by organizing NPI results using "factor structures" into subsyndromes [93, 133]. These frameworks may be pertinent in the future if we were to study more neuropsychiatrically troubled patients, but are not useful to our study sample.

v. On research question 1: patient's quality of life: interpretation using the literature

As the QOL-AD scale is composed of items that are rated from "poor", "fair", "good" to "excellent" [100, 101], our patients' rating of their own quality of life, then, was approximately "good". Caregivers rated the patient quality of life lower, somewhere between "fair" and "good".

Comparing QOL-AD results to the literature reiterated the importance of understanding the nuances of the tool or questionnaire when reading results.

Two separate American clinical trials of mild to moderate Alzheimer's disease patients offered an interesting comparison. Compared to both trials, our study sample was older, but was less cognitively impaired since a shorter period of time [106, 110]. However, in spite of differences in the severity of dementia, the QOL-AD of one trial approximated our results [106], while the QOL-AD of the other trial were found to be even greater than our healthier patient's scores [110]. Even more strikingly, an English study on patients living with severe dementia (average MMSE of 7.0) reported QOL-AD scores somewhere between “fair” and “good”, a quality of life which is not too far removed from the interpretation we made of our results [111].

We also noted that our study confirmed reports in the literature that caregiver reported QOL-AD is commonly lower than the patient’s own scoring of QOL-AD [106, 107, 110].

From these comparisons, we can conclude that QOL-AD may not decrease consistently as a patient’s cognitive abilities worsen, and may not drop as dramatically as one would expect even when descending to severe dementia. It is difficult to make full sense of QOL-AD in the context of a cross-sectional study; QOL-AD’s somewhat successful application in clinical trials (106, 110) suggests that the scale may be more useful in following the quality of life of a same population longitudinally instead. In sum, understanding of QOL-AD’s nuances is needed when reading QOL-AD results.

vi. On research question 2: needs of patients: interpretation using the literature

Generally, our patients reported few needs, which may be due to their relatively younger age and mild memory symptoms. Most of these needs were being met. The most prevalent needs surrounding “memory” and “physical health” were addressed through a combination of informal help from loved ones and formal help from professionals. “Money/budgeting”, “drugs” and “psychological distress”, the next most prevalent needs, were met mainly through informal assistance and support. For their “eyesight, hearing, communication”, patients relied on both informal and formal resources to meet their needs. The low number of unmet needs, on average below one per patient, is a reassuring finding considering the medical complexity of our patient population: a patient suffered on average 4.5 comorbid conditions (2.3, 1-8) and was prescribed 8.7 medications (2.3, 5-12).

We compared our results with two existing studies of needs of people with dementia living at home, which were also conducted with CANE, one in England, one in the Netherlands [118, 119]. In both cases, the patients were older and their cognition was more severely affected compared to our patients. Understandably, then, these studies’ patients expressed different needs than ours. Some similarities were still present: “memory”, “physical health” and “money/budgeting” were among the top needs in their studies like in ours. However, the more advanced cognitive decline of the English and the Dutch patients may have translated to needs in more basic aspects of daily living:

"food", "looking after the home", "mobility/falls", "self-care", "daytime activities" and "eyesight, communication, hearing".

We also noted that these European patients, like ours, tended to report fewer needs than their informal caregivers and professionals [118, 119]. For instance, the English study's caregivers rated patients' unmet needs differently than patients themselves; while the former were most concerned about providing the patient with "company" and "daytime activities", the latter were most concerned their "psychological distress" [118]. However, the more severe dementia suffered by these past studies' patients and their higher number of needs may have led to a wider, more apparent gap between the patient's own answers and their informal caregiver's perception of the situation. In other words, we observed underreporting of needs by patients though the difference was not as stark because our patients had fewer needs to begin with.

CANE results projected a vivid, systematic picture of our dementia patient population and their needs, and provided an avenue for comparison to other populations in place and in time. While our patients were not found to have as many needs as other populations, it is important to acknowledge the clinical significance that a single unmet need may have towards a person's quality of life.

vii. On research question 2: problems and needs of caregivers: interpretation using the literature

Overall, caregivers reported few problem areas, which again may be due to the dementia patients' relatively younger age and less severe disease on average. The most prevalent problem for caregivers was their "physical and psychiatric health", though results suggest this was adequately evaluated and followed in primary care. Indeed, "diagnosis or treatment of the carer by a GP" was reported as a met need by a similar number of caregivers. A trend is the reported "lack of information about dementia", "about treatment", "about services" and "disappointment caused by the illness, concerns about the patient's future". They were prevalent problems that remained unresolved, as caregivers showed great interest in "support from a social worker", "printed information material" among other resources but did not receive them at the time of study.

There was just one published study using CNA-D, which is the validation of the instrument conducted in Austria [126]. The differences in baseline characteristics of their caregivers compared to ours led to differences in problems, which in turn led to needs for different services.

Indeed, about half of the validation study's caregivers were the patients' children, which differs from our study where almost all caregivers were the spouse or partner. Consequently, the Austrian caregivers were much younger on average. Nevertheless, their caregivers, like our caregivers, were mostly female. Also, on average, the age and sex of patients for whom the Austrian caregivers cared for resembled our patient population. However, 40% of their patients lived in a nursing home while all of our patients still lived in the community.

These differences between the Austrian study population and ours, particularly the fact that around half of the Austrian caregivers were adult children of the patient, may explain differences in findings of caregiver problems. “Physical and psychiatric health” was of utmost importance to our caregivers, and it was a prevalent concern for their caregivers too. However, a majority of Austrian caregivers were “burned out or overstrained by care”, were “disappointed by the illness” and “did not have enough time for oneself” [126]. In contrast, our caregivers next biggest concern after their “physical and psychiatric health” was “lack of information”. The CNA-D painted two very different pictures, with the Austrian caregivers reporting many more and more varied problems than in our context of informal caregiving.

Differences in caregiver problems in our two populations led to differences in their needs for services. To address the Austrians’ “burnout” and related problems, caregivers and researchers most often expressed interest in “counselling and emotional support”, “relatives group guided by a professional”, “self-help group for family members” and forms of “psychoeducation” [126]. In our case, the caregivers turned towards the family physician for “diagnosis and treatment” to resolve their problems of “physical and psychiatric health”. Our caregivers wanted to consult a “social worker” and “printed information material” to learn and find answers because they “lacked information”, but these needs for services were not met.

On one hand, in our context of care, we had expected that the case manager would help resolve some of the reported problems, and provide or coordinate some services that were reported as being needed. On the other hand, it is plausible that the caregiver problems and needs would have been greater without the case manager. Regardless, caregiver problems were prevalent in our study population, as well as apparent shortcomings in attending to the caregivers’ needs for services. These findings are clinically relevant and the role of case management in supporting the informal caregiver should be investigated further.

It is interesting to note that in the sole existing CNA-D study besides ours, caregivers consistently underreported their problems and needs for services compared to the health professional’s or researcher’s assessment, a trend we observed in our study as well [126].

Overall, CNA-D generated an insightful profile of our caregiver population and provided an entry point to better understand their problems and needs and to reflect on the care and services provided to them.

viii. On research question 3 and 4: comparing Canadian born against foreign born patients and caregivers: interpretation using the literature

In general, our patients born in Canada and born elsewhere were retired and similarly educated. Foreign born patients, when compared to Canadian born patients, were found to have lower quality of life, more total needs and different needs. This echoes previous reports of inequalities in clinical outcomes experienced by ethnic minority but otherwise comparable dementia patients [27-30, 50-52], but we innovate by attempting to describe differences in terms of patient needs. However, in our case, such disparities may be explained in part by the presence of confounders. Indeed, foreign born patients had comparatively disadvantageous characteristics such as higher age, slightly earlier onset of memory symptoms, worse cognition and more severe behavioral symptoms. In fact, the ranges of MoCA scores of patients born inside and outside Canada barely overlapped. Contrary to reports in the literature [50-52], our study did not find conclusive evidence of inequality in the pharmacological treatment of memory symptoms between ethnic groups. Indeed, more foreign born patients were prescribed a cholinesterase inhibitor, and this may be due to their more advanced disease; cholinesterase inhibitors are indicated in dementia [128, 129] but not in mild cognitive impairment [130].

Interestingly, despite Canadian born patients being affected by more comorbidities and taking more medications, they reported a higher quality of life and fewer needs.

Likewise, differences were found between informal caregivers born inside and outside Canada. Despite being younger, foreign born caregivers reported more problems, and a different set of problems. The different problems reported by foreign born caregivers (e.g. more "burden"), then, determined their interest and need for different services (e.g. "respite care"). In addition, compared to their Canadian born counterparts, foreign born caregivers reported higher distress associated with the patient's behavior. The caregivers regardless of place of birth were mostly retired; however, a greater proportion of Canadian born caregivers received higher education than their foreign born peers, which may or may not contribute to other disparities observed. Though ultimately inconclusive, our results appeared to reflect the narrative of the literature on dementia caregiving and ethnocultural diversity: measurable and qualifiable differences often exist between two different ethnic groups of caregivers [27, 31, 43-45, 55].

Our findings on patient and caregiver differences between Canadian born and foreign individuals, though preliminary, are intriguing and merit further investigation. Our sample size did not allow for statistical testing, let alone stratified analyses, both of which should be required in future, larger studies of the same kind. One cofounder needing more attention is socioeconomic status as it is often thought to interact with ethnocultural diversity [29, 49, 134]. While we did evaluate education and work status, there are other measures that may be of interest and that could add to our understanding of a population's socioeconomic status [134-136].

Our eye comparison of the two ethnoculturally distinct groups, for now, remains entirely hypothesis generating. However, regardless of whether true differences existed between the two groups because of their different countries of birth, we can draw two conclusions from our results. First, we found that both groups of patients had a small number of unmet needs; through support from loved ones as well as primary care case management, both Canadian born and foreign born patients had most of their needs met. Second, we were concerned to find that both Canadian born and foreign born caregivers reported problems and needs that remain unaddressed, potential gaps in the case management and broader primary care that we provide. The reasons for the differences between Canadian born and foreign born caregivers remain to be investigated more thoroughly.

ix. Methodological considerations: choosing country of birth as explanatory variable

In the next paragraphs, we briefly contrast the concepts of culture and migration, we clarify their relationship and we explain why in our case, we decided to use migration as a proxy for culture despite the reductionism in doing so.

As defined previously, culture is "a collective expression for all behavior patterns acquired and socially transmitted through symbols. Culture includes customs, traditions, and language" [19]. Then, "a group of people with a common cultural heritage that sets them apart from others in a variety of social relationships" is an ethnic group, an ethnocultural group or an ethnicity [20].

Emigration and immigration is defined as "leaving one's country to establish residence in a foreign country" [137]. It is an important source of stress, and migrants, in spite of their heterogeneity, are traditionally classified as a vulnerable population [138-141]. So are ethnocultural minorities [142-147].

In a study of ethnocultural diversity, we concede that dividing participants into Canadian born and foreign born groups, i.e. by their immigration, is reducing the variety, richness and nuances of the different ethnicities involved. To understand why certain immigrants think differently than others, for instance, we would still need to divide further. In ideal circumstances, we would rather regroup the study population by their ethnic origins and examine each group's culture, of which immigration is a significant part.

Also, fixating on the criterion of immigration may allow a number of marginalized cultural groups to go unnoticed. All immigrants become, by default but to varying degrees, ethnic minorities in their new country of residence. However, not all ethnic minorities are immigrants, for example, the Afro-Americans in the United States and the Native Americans in North America. In addition, there are second or third generation immigrants, whose legal status may be indistinguishable from native citizens but the cultural ties to their foreign ancestors may still be strong, and unfortunately, these individuals may still be subject to prejudice and discrimination based on their inherited physical attributes or ethnic origins. In the context of the province of Quebec, French and English populations have real differences in culture, yet this dynamic would be lost or left in the background if immigration was the sole criterion.

Moreover, immigration's ability to predict marginalization varies from one study context to the next, depending on who is immigrating to where. For instance, a much greater proportion of immigrants settling in Germany will have to learn a new language than immigrants to Quebec. Indeed, many Quebec immigrations originate from English or French speaking countries, or had received prior education in these more popularly spoken languages compared to German. To explore in more detail how different immigrants interact differently with their new society, again we would be inclined to divide by individual ethnicities.

Though the country of birth and the immigration history represent a person's ethnicity imperfectly in more complex circumstances, in our case, the former factors proved to be accurate proxies for culture and ethnicity of our participants. All our Canadian born participants also grew up and live in Canada. At the same time, all our foreign born participants were also raised abroad, only arriving in Canada as adults. The formative years of Canadian born and foreign born participants are spent in different cultures, on different territories. As territory and culture are central in defining ethnicity [20], we argue that in our case, with our study participants, country of birth was a valid proxy for ethnicity. That said, the same approach may no longer be appropriate in future studies; for instance, we could be called upon to consider cases where a foreign born person had moved to Canada at a young age. If we were to continue pursuing larger investigations of the same nature, we may have to find a new explanatory variable to represent cultural diversity (e.g. ethnicity, language) that would be internally and externally valid; it will depend on the specific characteristics of this future study population, most important of which is its sample size.

In our pilot study, we complement this broad division based on country of birth with rich details describing the heterogeneity in our participants. Our quantitative data is valid and relevant and will serve as a platform for immediate follow-up research to address some concerns of reductionism mentioned above. Indeed, a qualitative study will quickly follow to explore the full ethnocultural diversity of our participants and how it colors their individual experiences of dementia through primary care case management.

x: Methodological considerations: insight on the recruitment process

Recruitment of persons affected by dementia can be complex and complicated and can be its own area of study. Existing literature on this subject tends to concern itself with the broad directions to take, the strategic decisions in recruitment, for instance, deciding on the use of patient registries or to recruit via community outreach, and considerations of time and costs, etc. [148-151] In our study, compared to the starting population, we recruited a modest number of study participants. In other words, we underwent a difficult recruitment, through which we learned to appreciate the technicalities and finer nuances in approaching this population.

Recruitment by telephone proved to have its strengths and weaknesses.

It allowed rapid recruitment of participants at the beginning. However, after the initial surge, we were left with large amounts of people not answering, requesting to call back at a later date or more firmly refusing to participate.

We deeply felt the fundamental limitations of the telephone. Through their voice, the recruiter needs to quickly establish trust with the caller, to communicate the study's information succinctly but accurately, and to navigate the caller's questions and concerns with tact. The recruiter has to know the study intimately, must think fast and act fast to garner the caller's interest, or to convert a caller's refusal without being impolite or appearing forced. In more than one way, the recruiter should embrace salesmanship, which is an art, a mastery. This is not mentioning the technical limitations of the telephone, for example, when speaking with elderly individuals with hearing difficulties, or limited knowledge of English or French, on a poor connection.

If offered a second chance, we would have planned early to meet and recruit patients in clinic, in person. We would engage the case manager or the physician, which could essentially resolve all issues of credibility and trust. Body language and visual cues, which are often taken for granted until they are unavailable, would allow more personal communication to occur between the recruiter and the potential participant, and would facilitate the building of a privileged relationship. It would be easier to explain the study too, perhaps with the help of visual support. Speaking face to face would also give the recruiter more time and more room to maneuver if the patient or the caregiver refuses initially. Though staking out the clinic appears time intensive, it could have improved our response rate.

In conclusion, when faced with a large population and limited time and personnel, the telephone is a fast and convenient approach to enroll participants. However, its reach is limited particularly when targeting an elderly, frail population. When working with smaller populations, recruiting in person may be worth the investment of extra manhours.

xi. Methodological considerations: on patient’s and caregiver’s underreporting

The patient’s and the caregiver’s understatement of their own difficulties was a recurring finding throughout different parts of our results, consistent with the findings of previous studies using these instruments [118, 119, 126]. We highlight why recording multiple perspectives is essential to represent and understand the “truth” lived by these individuals.

Though the current narrative in medicine and healthcare is one of person-centeredness, patients and caregivers alike are questioned intensively during the course of data collection, are often asked difficult questions and can become tired or stressed. Thus, in the moment, the answer they give to a particular question on their problem or need may not always reflect their reality, which is often made clear to the interviewer during other parts of the conversation. For example, a caregiver may say that their visits to the clinic always felt rushed, and they were upset that they still are not clear on what dementia is and what it means for the future. However, later on in the interview when asked the same question on “lack of information” from the questionnaire, the caregiver may brush it off, perhaps because they just thought of how poorly the patient slept and wanted the interviewer to know. Or perhaps, they were tired, did not want to repeat themselves and felt that they have complained too much. We respect the patient’s and caregiver’s take on their own situation tremendously, but we understand why CANE and CNA-D also report a third party's perspective, because an interviewer can contribute valuable professional knowledge and experience in assessing the situation. In any case, providing multiple perspectives certainly help in representing the intricacies of clinical reality.

xii. Methodological considerations: using different questionnaires and the synergy therein

In more than one instance, we realized the benefits of using questionnaires that appears to overlap each other; while the data generated may seem redundant at first, it enabled the interpretation of our results to more accurately describe a complex reality.

One illustrative example is the synergy observed between NPI and CANE. Indeed, while CANE revealed patient's "psychological distress" as a prevalent need, NPI enriched this finding by identifying "depression" and "sleep and nighttime behavior disorders" as the most common neuropsychiatric manifestations of dementia experienced by our patients.

Different questionnaires may not always confirm each other's results; obtaining divergent results may be equally insightful. For example, just 2 caregivers reported through the CNA-D that they were "burdened by behavioral problems of the patients", but 9 caregivers reported some distress associated with such symptoms in the NPI. Albeit not entirely contradictory, these results added different pieces of evidence to construct the truth: few caregivers felt "burdened" by these problems, but many more had experienced them and were distressed but to a lesser degree.

NPI and CNA-D are synergistic in another way. While NPI generated a caregiver distress score, CNA-D allowed the identification of services that are potentially beneficial to the caregiver. In our case, many caregivers reported such distress, and in turn showed interest in various mental health resources such as "counselling", "relatives group guided by a professional", "individual" and "group psychoeducation", needs that were unmet.

In brief, using multiple questionnaires that appear to have redundancies may prove more interesting than it first seems, and may help triangulate findings to more faithfully represent the nuances of the real world.

xiii. Methodological considerations: a caveat about questionnaire results

The CANE and CNA-D (but also NPI and QOL-AD) share a feature that merits careful consideration when reading results: they assign the same numerical value to different items, which in reality, may not be equally important to particular patient compared to another. Reading our study's tables and graphs, some may be drawn to the low number of unmet patient needs, or the wide white areas in the graphs indicating no problem in many aspects of a caregiver's life. However, not all of the graph needs to be black for things to be bad. A single need or problem has the potential of consuming an individual's life. In giving the same weight to each problem or need, CANE and CNA-D, particularly their graphical representations, can mislead the inattentive reader to underappreciate the difficulties lived by dementia patients and caregivers. In practice, not all needs are created equal. For instance, basic human needs such as eating and having an appropriate place to live are intrinsically different from the relatively higher pursuits of having company and a fulfilling intimate relationship. Then again, different individuals appreciate different needs differently; each need uncovered may be clinically significant in the eyes of the caregiver or the patient, and each need must be treated with seriousness notwithstanding its statistical significance.

b. Limitations

The population was difficult to recruit resulting in a small sample that could not be deemed representative of the patient population of the study site, nor the patient population of the broader Canadian context of care. Consequently, present results are hypothesis generating. Future analyses aiming to compare Canadian born and foreign born dementia populations should aim to take into account differences in age, sex, education, socioeconomic status, onset of symptoms and other relevant characteristics.

While we hope that the pilot study will find a degree of generalizability or transferability, we remain cautious because our study context is unique in many ways. The Herzl clinic is set in a specific neighborhood of Montreal; serves and is in turn influenced by a particular, ethnoculturally diverse clientele; grew under the organizational culture of the Jewish General Hospital; operates within the anglophone healthcare network, which coexists with a francophone counterpart in the city. Observations made elsewhere in Montreal may very well contradict our findings.

Additionally, we could not capture all ethnicities of potential interest to the medical and research communities or their richness of each culture and ethnicity, reducing our narrative to just two groups due to sample size, time and resources. However, we provided detailed statistical description of our study participant's great heterogeneity.

There may also be cultural groups living with dementia but who do not pursue care and who remain outside of the mainstream medical system. Moreover, there are dementia patients living in the community with no identifiable caregiver, with unique needs and challenges deserving of further study.

Our study was solely concerned with the service users' perspectives. We would want to eventually involve service providers as well, so to complete the picture of case management, a dialogue and an exchange between providers and users.

We therefore highlight the exploratory nature of the current pilot study. Our data remains valid, rich and relevant, and is a solid start for more extensive research in the area.

c. Conclusions

Our pilot study is an entry point to explore the local ethnocultural diversity of dementia patients and their informal caregivers.

We determined that the Herzl Family Practice Centre, through case management, served a dementia population with rich and varied cultural origins. The patients were comparatively young and in the earlier stages of cognitive decline, but were beginning to show behavioral symptoms associated with dementia. They also had on average several comorbidities and were prescribed multiple medications, though they enjoyed a good quality of life. In spite of the patients' medical complexity and many needs ("memory", "physical health", etc.), these needs were mostly met through the support of loved ones and dementia case management. Caregivers reported problems ("lack of information") not yet addressed, and needs for services ("support from a social worker") that have not been met.

Differences were observed between Canadian born and foreign born participants. Because of the small sample size, results are hypothesis generating. On average, foreign born patients had more needs, different needs and lower quality of life compared to their Canadian born counterparts. This may be confounded by foreign born patient's older age, longer onset of memory symptoms, worse cognition and more behavioral symptoms. Foreign born caregivers were younger than their Canadian born peers, but reported more stress associated with their patient's behavioral symptoms, more problems overall (and different problems) and more needs (and different needs) for services. Though lacking statistical significance, these findings may be clinically impactful in the care of our patient population.

We gained valuable experience and insight about the feasibility of this type of research in the local setting, particularly in matters of recruitment and data collection with this vulnerable patient population. The limitations of our pilot study are threads to follow in future, larger endeavours. A more wholistic understanding of the local context of primary care dementia case management is needed. The role that cultural diversity can play in this complex environment merits further investigation, in order to better serve all members of a population already vulnerable by age and disease.

d. Future Directions

i. Knowledge dissemination

Knowledge dissemination would adopt a participatory undertone. Our vision is to involve a variety of stakeholders, which would include willing patients and their caregivers, case managers, family physicians, other allied health professionals of the team and higher decision-makers. We would hold an interactive educational meeting at the study site, first to present, interpret and validate study findings, and second, if applicable, to generate discussion for emerging solutions. We hope to inspire fellow researchers and our future selves in this grand discussion. More importantly, we hope that the exchange can empower service users in taking charge of their own stories and oversee, to a degree, the progress of their data towards people of authority capable of enacting change. Through our study or future work, we also want to empower professionals directly involved in patient care, to provide them with previously unknown or ignored perspectives that may immediately inform their practices, and to assist them in advocating for a system with the appropriate, tailored resources to better fulfill their patients' needs. At last, perhaps through a combination of efforts further beyond our one study, we desire to empower governance of different levels with the key piece of evidence — the user needs — that is central to more efficiently and more justly allocating limited healthcare resources.

Concretely, our study was and will be tied to the following dissemination initiatives:

a. Ministry of Health and Social Services report on the Alzheimer Plan of Quebec under supervision of la directrice générale adjointe des services aux aînés, Nathalie Rosebush
b. Canadian Dementia Knowledge Translation Network led by Canadian Institutes of Health Research

c. Réseau-1 Québec, un réseau de connaissances en services et soins de santé intégrés de première ligne
d. McGill Primary Health Care Research network
e. Relevant annual scientific conferences: North American Primary Care Research Group Annual Meeting, Annual Lady Davis Institute Scientific Retreat
f. One article in a relevant peer-reviewed journal

ii. Future investigations

We recommend a follow-up qualitative descriptive study of the same study population, in order to fully explore the ethnocultural heterogeneity of our participants, and how cultural differences may or may not determine their problems, needs and healthcare experiences. We are interested in the accounts they give to their journey with the illness through case management in a primary care setting: the who, what, where and how. More precisely, we want to dive deeper into the participants' cultural identifications, their evolution with dementia, contributing factors to their needs, perception of case management, case managers and broader team, and suboptimal outcomes. We may consider interviewing the clinical staff as well, so to document and analyze their perception and understanding of the reality of caring for an ethnoculturally diverse dementia population. Qualitative results will complement and help interpret our pilot study's quantitative results.

A multisite study is in the planning to examine additional Family Medicine Groups in Montreal where dementia case management has been implemented. Future studies should recruit a greater variety of study participants in greater numbers, for example, by including people living with dementia in the community without an informal caregiver.

Chapter 6: References

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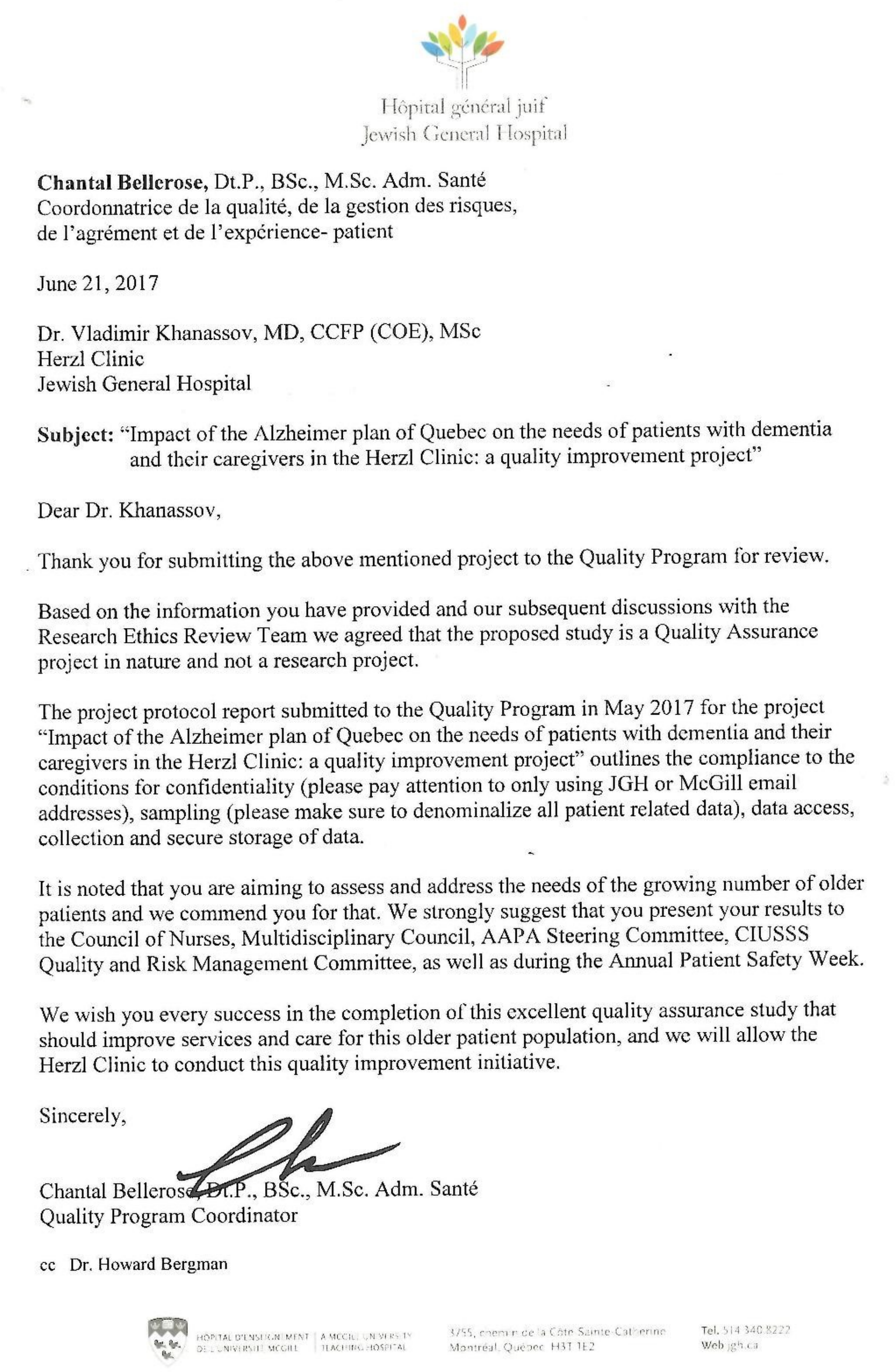
Appendix

Appendix I. Ethics approval



Hôpital général juif
Jewish General Hospital

Chantal Bellerose, Dt.P., BSc., M.Sc. Adm. Santé
Coordonnatrice de la qualité, de la gestion des risques,
de l'agrément et de l'expérience- patient

June 21, 2017

Dr. Vladimir Khanassov, MD, CCFP (COE), MSc
Herzl Clinic
Jewish General Hospital

Subject: "Impact of the Alzheimer plan of Quebec on the needs of patients with dementia and their caregivers in the Herzl Clinic: a quality improvement project"

Dear Dr. Khanassov,

Thank you for submitting the above mentioned project to the Quality Program for review.

Based on the information you have provided and our subsequent discussions with the Research Ethics Review Team we agreed that the proposed study is a Quality Assurance project in nature and not a research project.

The project protocol report submitted to the Quality Program in May 2017 for the project "Impact of the Alzheimer plan of Quebec on the needs of patients with dementia and their caregivers in the Herzl Clinic: a quality improvement project" outlines the compliance to the conditions for confidentiality (please pay attention to only using JGH or McGill email addresses), sampling (please make sure to denominalize all patient related data), data access, collection and secure storage of data.

It is noted that you are aiming to assess and address the needs of the growing number of older patients and we commend you for that. We strongly suggest that you present your results to the Council of Nurses, Multidisciplinary Council, AAPA Steering Committee, CIUSSS Quality and Risk Management Committee, as well as during the Annual Patient Safety Week.

We wish you every success in the completion of this excellent quality assurance study that should improve services and care for this older patient population, and we will allow the Herzl Clinic to conduct this quality improvement initiative.

Sincerely,

Chantal Bellerose, Dt.P., BSc., M.Sc. Adm. Santé
Quality Program Coordinator

cc Dr. Howard Bergman

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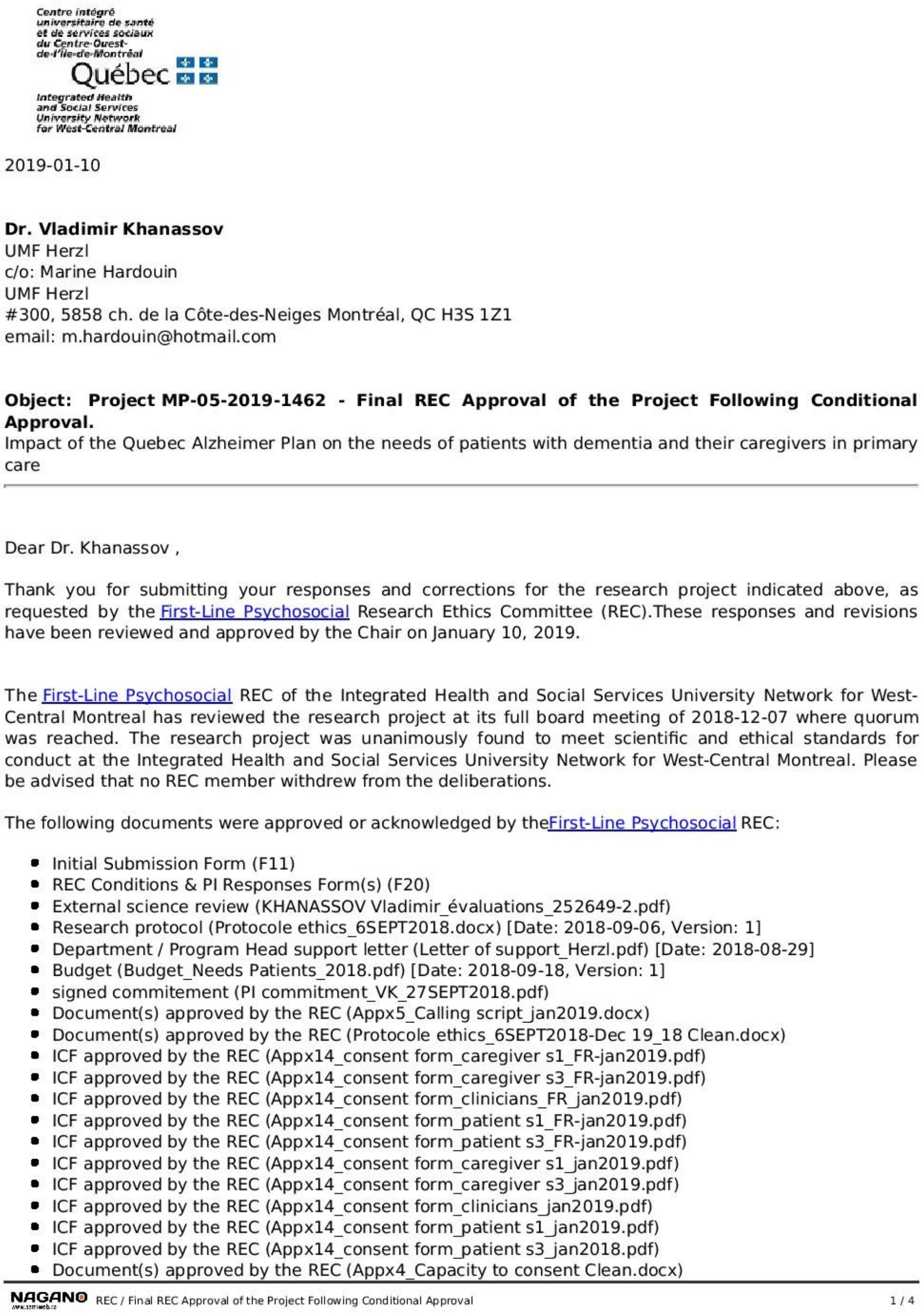
Appendix I. Ethics approval (cont'd)



Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal
Québec
Integrated Health
and Social Services
University Network
for West-Central Montreal

2019-01-10

Dr. Vladimir Khanassov
UMF Herzl
c/o: Marine Hardouin
UMF Herzl
#300, 5858 ch. de la Côte-des-Neiges Montréal, QC H3S 1Z1
email: m.hardouin@hotmail.com

Object: Project MP-05-2019-1462 - Final REC Approval of the Project Following Conditional Approval.
Impact of the Quebec Alzheimer Plan on the needs of patients with dementia and their caregivers in primary care

Dear Dr. Khanassov ,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the First-Line Psychosocial Research Ethics Committee (REC).These responses and revisions have been reviewed and approved by the Chair on January 10, 2019.

The First-Line Psychosocial REC of the Integrated Health and Social Services University Network for West-Central Montreal has reviewed the research project at its full board meeting of 2018-12-07 where quorum was reached. The research project was unanimously found to meet scientific and ethical standards for conduct at the Integrated Health and Social Services University Network for West-Central Montreal. Please be advised that no REC member withdrew from the deliberations.

The following documents were approved or acknowledged by theFirst-Line Psychosocial REC:

- Initial Submission Form (F11)
- REC Conditions & PI Responses Form(s) (F20)
- External science review (KHANASSOV Vladimir_évaluations_252649-2.pdf)
- Research protocol (Protocole ethics_6SEPT2018.docx) [Date: 2018-09-06, Version: 1]
- Department / Program Head support letter (Letter of support_Herzl.pdf) [Date: 2018-08-29]
- Budget (Budget_Needs Patients_2018.pdf) [Date: 2018-09-18, Version: 1]
- signed commitement (PI commitment_VK_27SEPT2018.pdf)
- Document(s) approved by the REC (Appx5_Calling script_jan2019.docx)
- Document(s) approved by the REC (Protocole ethics_6SEPT2018-Dec 19_18 Clean.docx)
- ICF approved by the REC (Appx14_consent form_caregiver s1_FR-jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_caregiver s3_FR-jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_clinicians_FR_jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_patient s1_FR-jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_patient s3_FR-jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_caregiver s1_jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_caregiver s3_jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_clinicians_jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_patient s1_jan2019.pdf)
- ICF approved by the REC (Appx14_consent form_patient s3_jan2018.pdf)
- Document(s) approved by the REC (Appx4_Capacity to consent Clean.docx)

Appendix I. Ethics approval (cont'd)

- Document(s) approved by the REC (Appx11_MedEcho collection_dec2018.docx)
- Document(s) approved by the REC (Appx13_Clinician information.docx)
- Document(s) approved by the REC (Appx12_Interview script.docx)
- Document(s) approved by the REC (Appx7_CANE_FR.pdf)
- Document(s) approved by the REC (Appx7_CANE_ENG.pdf)
- Document(s) approved by the REC (Appx6_MoCA_FR.pdf)
- Document(s) approved by the REC (Appx6_MoCA_ENG.pdf)
- Document(s) approved by the REC (Appx6_MMSE_ENG(1).pdf)
- Document(s) approved by the REC (Appx6_MMSE_FR.pdf)
- Document(s) approved by the REC (Appx3_Sample size.docx)
- Document(s) approved by the REC (Appx2_Sites.docx)
- Document(s) approved by the REC (Appx1_Context.docx)
- Document(s) approved by the REC (Appx16-PM.docx)
- Document(s) approved by the REC (Appx8_CNA-D_ENG.doc)
- Document(s) approved by the REC (Appx8_CNA-D_FR.pdf)
- Document(s) approved by the REC (Appx9_NPI_ENG.pdf)
- Document(s) approved by the REC (Appx9_NPI_FR.pdf)
- Document(s) approved by the REC (Appx10_QOL-AD_ENG.pdf)
- Document(s) approved by the REC (Appx10_QoL-AD_FR.pdf)

The responses and revisions will be reported to the FLP REC meeting on February 8, 2019.

Please be advised that you may only initiate the research project after all required reviews and decisions are received and documented.

The approval of the research project is valid until 2019-12-07.

All research involving human subjects requires review at recurring intervals. To comply with the regulation for continuing review of at least once per year, it is the responsibility of the investigator to submit an Annual Renewal Submission Form (F9) to the REC prior to expiry. Please be advised that should the protocol reach its expiry before a continuing review has been submitted, the data collected after the expiry date may not be considered valid. However, should the research conclude for any reason prior to approval expiry, you are required to submit a Completion (End of a Study) Report (F10) to the REC once the data analysis is complete to give an account of the study findings and publication status.

Furthermore, should any revision to the project or other development occur prior to the next continuing review, you must advise the REC without delay. Regulation does not permit initiation of a proposed study modification prior to its approval by the REC.

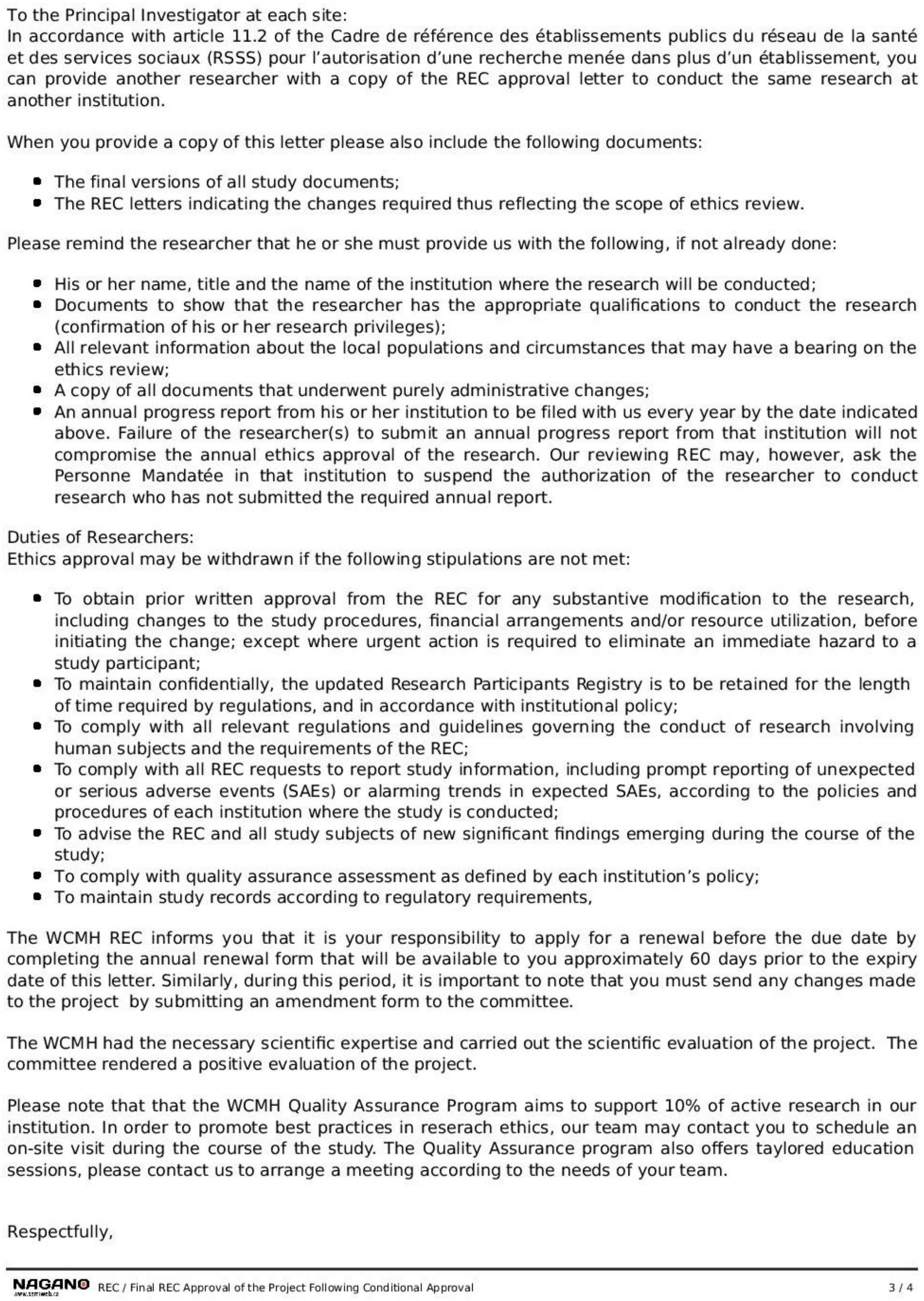
The Research Ethics Committees of the Integrated Health and Social Services University Network for West-Central Montreal (Federalwide Assurance Number: 0796) are designated by the province (MSSS) and follows the published guidelines of the TCPS 2 - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014), in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998), and the membership requirements for Research Ethics Committee defined in Part C Division 5 of the Food and Drugs Regulations; and acts in conformity with standards set forth in the United States Code of Federal Regulations governing human subjects research, and functions in a manner consistent with internationally accepted principles of good clinical practice.

If you want to conduct this research in another institution of the RSSS:

In accordance with article 11.1 of the Cadre de référence des établissements publics du réseau de la santé et des services sociaux (RSSS) pour l'autorisation d'une recherche menée dans plus d'un établissement, you may submit a copy of this letter to a public institution of the RSSS where you would seek authorization to conduct the research within their walls or under their auspices.

If an institution asks you to make administrative changes to the final version of a document approved by our REC, please take the appropriate measures for our REC to receive a copy of the modified document in "track-changes" in order to clearly show the changes made to the document.

Appendix I. Ethics approval (cont'd)



To the Principal Investigator at each site:
In accordance with article 11.2 of the Cadre de référence des établissements publics du réseau de la santé et des services sociaux (RSSS) pour l'autorisation d'une recherche menée dans plus d'un établissement, you can provide another researcher with a copy of the REC approval letter to conduct the same research at another institution.

When you provide a copy of this letter please also include the following documents:

- The final versions of all study documents;
- The REC letters indicating the changes required thus reflecting the scope of ethics review.

Please remind the researcher that he or she must provide us with the following, if not already done:

- His or her name, title and the name of the institution where the research will be conducted;
- Documents to show that the researcher has the appropriate qualifications to conduct the research (confirmation of his or her research privileges);
- All relevant information about the local populations and circumstances that may have a bearing on the ethics review;
- A copy of all documents that underwent purely administrative changes;
- An annual progress report from his or her institution to be filed with us every year by the date indicated above. Failure of the researcher(s) to submit an annual progress report from that institution will not compromise the annual ethics approval of the research. Our reviewing REC may, however, ask the Personne Mandatée in that institution to suspend the authorization of the researcher to conduct research who has not submitted the required annual report.

Duties of Researchers:
Ethics approval may be withdrawn if the following stipulations are not met:

- To obtain prior written approval from the REC for any substantive modification to the research, including changes to the study procedures, financial arrangements and/or resource utilization, before initiating the change; except where urgent action is required to eliminate an immediate hazard to a study participant;
- To maintain confidentially, the updated Research Participants Registry is to be retained for the length of time required by regulations, and in accordance with institutional policy;
- To comply with all relevant regulations and guidelines governing the conduct of research involving human subjects and the requirements of the REC;
- To comply with all REC requests to report study information, including prompt reporting of unexpected or serious adverse events (SAEs) or alarming trends in expected SAEs, according to the policies and procedures of each institution where the study is conducted;
- To advise the REC and all study subjects of new significant findings emerging during the course of the study;
- To comply with quality assurance assessment as defined by each institution's policy;
- To maintain study records according to regulatory requirements,

The WCMH REC informs you that it is your responsibility to apply for a renewal before the due date by completing the annual renewal form that will be available to you approximately 60 days prior to the expiry date of this letter. Similarly, during this period, it is important to note that you must send any changes made to the project by submitting an amendment form to the committee.

The WCMH had the necessary scientific expertise and carried out the scientific evaluation of the project. The committee rendered a positive evaluation of the project.

Please note that that the WCMH Quality Assurance Program aims to support 10% of active research in our institution. In order to promote best practices in reserach ethics, our team may contact you to schedule an on-site visit during the course of the study. The Quality Assurance program also offers taylored education sessions, please contact us to arrange a meeting according to the needs of your team.

Respectfully,

NAGANO REC / Final REC Approval of the Project Following Conditional Approval 3 / 4

Appendix I. Ethics approval (cont'd)

Me. Alain Klotz
Me Alain Klotz, LL.B., LL.M.
Chair, First-Line Psychosocial Research Ethics Committee

FWA 00000796

Appendix II.

CANE: met and unmet needs of patients with memory issues: number and percentage of patients with a need, reported by the patient, their caregiver and the researcher (n=15)

	Number of patients with this met need (number, %)			Number of patients with this unmet need (number, %)		
	patient	caregiver	researcher	patient	caregiver	researcher
1. Accommodation	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
2. Looking after the home	2 (13.3%)	4 (26.7%)	4 (26.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
3. Food	1 (6.7%)	1 (6.7%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
4. Self-care	1 (6.7%)	1 (6.7%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
5. Caring for someone else	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
6. Daytime activities	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
7. Memory	13 (86.7%)	14 (93.3%)	14 (93.3%)	2 (13.3%)	1 (6.7%)	1 (6.7%)
8. Eyesight/ hearing/ communication	4 (26.7%)	4 (26.7%)	4 (26.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
9. Mobility/ falls	2 (13.3%)	3 (20.0%)	3 (20.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
10. Continence	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (6.7%)	1 (6.7%)
11. Physical health	11 (73.3%)	11 (73.3%)	13 (86.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
12. Drugs	4 (26.7%)	3 (20.0%)	4 (26.7%)	0 (0.0%)	1 (6.7%)	1 (6.7%)
13. Psychotic symptoms	1 (6.7%)	1 (6.7%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
14. Psychological distress	4 (26.7%)	3 (20.0%)	2 (13.3%)	0 (0.0%)	2 (13.3%)	1 (6.7%)
15. Information	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
16. Deliberate self-harm	0 (0.0%)	1 (6.7%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
17. Inadvertent self-harm	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
18. Abuse-neglect	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
19. Behavior	1 (6.7%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (6.7%)
20. Alcohol	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
21. Company	1 (6.7%)	2 (13.3%)	2 (13.3%)	1 (6.7%)	0 (0.0%)	0 (0.0%)
22. Intimate relationships	2 (13.3%)	1 (6.7%)	1 (6.7%)	0 (0.0%)	1 (6.7%)	1 (6.7%)
23. Money/ budgeting	5 (33.3%)	7 (46.7%)	6 (40.0%)	1 (6.7%)	1 (6.7%)	1 (6.7%)
24. Benefits	1 (6.7%)	1 (6.7%)	0 (0.0%)	1 (6.7%)	1 (6.7%)	1 (6.7%)

Appendix III.

CNA-D: number of moderate and serious problems of the informal caregivers as reported by the caregiver and the researcher (n=15)

Problem area	Number of caregivers who reported this area as a moderate problem		Number of caregivers who reported this area as a serious problem	
	Caregiver's answer	Researcher's assessment	Caregiver's answer	Researcher's assessment
1. Lack of information about dementia	1	9	1	1
2. Lack of information about treatment	1	4	2	2
3. Lack of information about services	2	4	1	1
4. Financial burden	0	0	0	0
5. Legal issues	3	3	0	0
6. Disappointment caused by the illness, concerns about the patient's future	3	4	1	1
7. Communication problems and conflicts with the patient	1	1	1	1
8. Burdened by behavioral problems of the patients	1	1	1	1
9. Problems caused by crises	0	0	0	0
10. Not enough time for oneself (including caring for the patient when the relative becomes sick)	1	1	0	0
11. Social isolation, conflicts within the family	2	2	1	1
12. Burden caused by dangerous situations	1	1	0	0
13. Fear of stigmatization and discrimination	0	0	0	0
14. Feelings of guilt, being blamed	0	0	0	0
15. Missing nursing skills	0	0	0	0
16. Difficulties concerning household tasks	1	1	0	0
17. Burned out or overstrained by care	1	1	0	0
18. Physical or psychiatric illness of the carer	7	8	1	1
19. Others	1	1	0	0

Appendix IV.

CNA-D: met and unmet (or partially met) needs of the informal caregivers as reported by the caregiver and the researcher (n=15)

Service or resource for informal caregiver	Number of caregivers with this met need (intervention is needed and sufficiently received)		Number of caregivers with this unmet or partially met need (intervention is needed, but not received or received, but insufficiently)	
	Caregiver's answer	Researcher's assessment	Caregiver's answer	Researcher's assessment
Counseling and emotional support	0	0	3	4
Relatives group guided by a professional	0	0	3	4
Self-help group for family members	1	1	2	3
Individual psychoeducation	0	0	3	3
Printed information material	0	0	5	5
Support from a social worker	0	0	6	7
Group psychoeducation	0	0	4	4
Financial compensation	0	0	0	0
Temporary supervision of the patient at home	0	0	1	1
Care for the patient in a day center	0	0	2	2
Mobile personal care for outpatients	1	1	0	0
Training of practical skills for the carer (e.g. basic nursing skills)	0	0	0	0
Diagnosis or treatment of the carer by a GP	7	7	2	2
Mobile nursing care for outpatients	0	0	0	0
Holidays together with the patient in a specialized setting	0	0	0	0
Respite care	0	0	1	1
General assistance for household chores	1	1	0	0
Hotline, where the carer can get advice in crises	0	0	0	0
Psychotherapy	1	1	1	1
Social contact service	0	0	1	1
Mobile crisis service visiting the family at home	0	0	0	0
Specialized services to help with specific household tasks (e.g. laundry service)	0	0	0	0
Meals-on-wheels	0	0	1	1
Initiating to become a legal administrator	1	1	1	1