

The Cultural Diversity of Dementia Patients and Caregivers in Primary Care Case Management: a Pilot Mixed Methods Study



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ABSTRACT

Context

The Canadian reality of dementia care may be complicated by the cultural diversity of patients and their informal caregivers.

Objectives

To what extent do needs differ between Canadian- and foreign-born patients and caregivers? What are their experiences with the illness in primary care case management?

Methods

Mixed methods, sequential explanatory design (a cross-sectional study, followed by a qualitative descriptive study), involving 15 pairs of patients and caregivers.

Results

Foreign-born patients had more needs compared to their Canadian-born counterparts. Foreign-born caregivers reported more stress, more problems, and increased need for services. However, the reported experiences of Canadian- vs. foreign-born individuals were similar.

Conclusion

The results remain hypothesis-generating. The present pilot illustrated the suitability of mixed methods to this area of study, which deserves further investigation to better serve all members of a population already vulnerable by age and disease.

Key words: dementia, culture, ethnicity, mixed methods study

INTRODUCTION

Dementia (or major neurocognitive disorder) is a set of neurodegenerative diseases characterized by progressive cognitive decline affecting daily activities. The projected growth of its

prevalence and associated societal burden over the coming years is impressive, in Canada^(1,2) and worldwide.⁽³⁾ Pending the arrival of definitive treatment, clinicians, administrators, and policymakers look to optimize health services and their delivery, in order to improve the patient's and their informal caregiver's quality of life. Following Canadian consensus conferences,⁽⁴⁾ the Alzheimer Plan in the Canadian province of Quebec reoriented the responsibilities of diagnosis and treatment of dementia to the family physicians and interdisciplinary primary care teams.^(5,6) In supporting them, select Family Medicine Groups adopted case management, utilizing the case manager's expertise to provide continuous, comprehensive, and person-centred care and support.⁽⁵⁻⁷⁾

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".^(8,9) In practice, a case manager is often a nurse or a social worker. They perform an initial assessment of the patient, and a care plan is drawn in conjunction with the patient and their informal caregiver. The case manager will follow up longitudinally, responding to their evolving clinical situation in concert with the family physician, allied health professionals, and other resources.

There is favourable evidence for the use of case management in dementia care:⁽⁷⁾ though its implementation can be inconsistent,^(10,11) a meta-analysis demonstrated case management's positive impact on patient's behavioural symptoms and caregiver's confidence in providing care.⁽¹²⁾ However, little research has been conducted on how the model would cater to a culturally diverse population of dementia patients and caregivers.

Canada, and Montreal in particular, are diverse in their cultural constituents. In Montreal, between a quarter and

a half of the inhabitants are immigrants or non-permanent residents, a fifth to a quarter are able to speak a non-official language, all grouped into more than 250 reported ethnicities.^(13,14) In such an environment, added to the complexity of dementia care, there is risk for inequality between ethnic groups. There is a wealth of studies detailing how different ethnicities are affected by dementia differently, from quantitative studies on the epidemiology in ethnic groups (e.g., disparities in prevalence among ethnic groups) to qualitative studies of these groups' experiences with the illness (e.g., stigmatization).⁽¹⁵⁻³⁶⁾ Cultural diversity also affects dementia care and care delivery in complex ways (e.g., cross-cultural performance of clinical tools, disparities in clinical outcomes between ethnic groups).^(15-18,25,37-43)

Case management is a dynamic process shaped by the cultural past of its users and providers.^(9,44-56) However, cultural studies of dementia and case management are conducted in specific settings with specific populations (e.g., Vietnamese Americans in the United States^(21,27) or non-Western immigrants in the Netherlands⁽¹⁸⁾) and the conclusions drawn are likely not transferable elsewhere. The present pilot study, then, was a first insight into the primary care dementia case management of culturally diverse patients and their informal caregivers. Our research questions were: (a) To what extent does the number of needs differ between dementia patients and their informal caregivers born in vs. outside of Canada? and (b) What accounts do these culturally distinct groups of patients and caregivers give of their experiences with the illness through case management in a primary care setting?

METHODS

Study Design and Setting

We conducted a pilot mixed methods, sequential explanatory study (to help develop a larger multisite study).⁽⁵⁷⁾ It consisted of quantitative phase (cross-sectional study), followed by a qualitative phase (qualitative descriptive study). The study focused on one Family Medicine Group that adopted dementia case management, the Herzl Family Practice Centre of the Jewish General Hospital (a teaching tertiary hospital).

Study Population and Eligibility Criteria

The population of interest was mild cognitive impairment (MCI) or mild-to-moderate dementia patients and their informal caregivers living in the community. We attempted to recruit all eligible patients and caregivers of the study site.

Inclusion criteria for patients were as follows: patient suffers MCI^(58,59) or mild-to-moderate dementia,^(59,60) scoring Montreal Cognitive Assessment (MoCA) above 10 and Mini-Mental State Examination (MMSE) above 16. Note that these cut-off scores are equivalent for moderate dementia; we relied primarily on MoCA cut-off because of its superior performance in milder disease, then calculated the equivalent MMSE cut-off based on several publications on conversion between these two tools (including a validation study in an ethnically diverse population).⁽⁶¹⁻⁶³⁾ We chose to focus on

MCI or mild-to-moderate dementia so as to gain information directly from the patient; at this stage of their disease, they remain able to report feelings and express concerns about their condition).⁽⁶⁴⁾ Other inclusion criteria included: 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;^(59,60) suffers from dementia secondary to alcohol abuse, HIV/AIDS or brain tumour; 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 their medical visits (the majority of visits, on a recurring basis), and/or spends at least our hour per day, four days per week in direct contact with the patient unpaid. Exclusion criteria for the informal caregivers were as follows: none.

Phase 1, Quantitative: a Cross-Sectional Study of Needs

To answer the first research question (quantitative), we performed a cross-sectional study. The outcome variables are problems and needs of patients and caregiver. These were measured by administering two clinically and research-validated questionnaires. The Camberwell Assessment of Need for Elderly (CANE) measured "patient needs",⁽⁶⁵⁾ a tool that is validated across a multitude of settings linguistically and culturally.⁽⁶⁶⁻⁶⁹⁾ The Carers' Needs Assessment for Dementia (CNA-D) measured "caregiver problems" and their "needs for services",⁽⁷⁰⁾ the only available instrument specifically designed and validated for dementia caregiver needs.⁽⁷¹⁾

The explanatory variable is being born (and reaching adulthood) in Canada vs. abroad. We also assessed the patient's cognitive impairment using the MMSE and MoCA.⁽⁷²⁻⁷⁴⁾ We collected sociodemographic and other background information, including treatment with a cholinesterase inhibitor,^(75,76) behavioural manifestations of dementia and associated caregiver distress using the Neuropsychiatric Inventory (NPI),⁽⁷⁷⁻⁷⁹⁾ as well as patient quality of life using the Quality of Life-Alzheimer's Disease scale (QOL-AD).^(80,81)

However, due to the small sample size, no statistical testing was conducted; we rely on descriptive statistics and report mean, standard deviation, range. Comparisons made hereafter are hypothesis-generating.

Phase 2, Qualitative: a Descriptive Study

To answer the second research question (qualitative), we then performed a qualitative descriptive study, wanting to produce a comprehensive summary of the patients' and caregivers' accounts of the who, what, and where of their experiences, in order to explain or compliment quantitative results. We purposively sampled from participants of the quantitative phase, selecting Canadian-born vs. foreign-born individuals (6 patients and 6 caregivers) with a contrasting number of needs. We sampled to data saturation, meaning we collected

and analyzed data until no more new findings were discovered and further data were judged unnecessary.⁽⁸²⁾ The first author conducted individual, semi-structured interviews with patients and caregivers separately. Our interview guide was refined iteratively as we gathered data, covering the participants' cultural identifications, evolution with dementia, contributing factors to their needs, perception of case management, case managers and broader team, and suboptimal outcomes. Transcripts were produced from audio recordings; when participants declined to be recorded, the interviewer wrote down field notes instead.

We applied thematic content analysis both deductively and inductively⁽⁸³⁾ to the interview transcripts and field notes, trying accurately and parsimoniously to capture the participants' responses into themes. We drew from an existing theoretical framework on cultural competency by Jirwe *et al.*⁽⁸⁴⁾ However, this framework was conceived from the service providers' perspective, which is why we adapted, interpreted, and added to the framework by proceeding both deductively and inductively. The first author coded the interviews, developing a scheme which is discussed with the third author in an iterative process, debriefing frequently.

We undertook a number of other measures, as outlined by Shenton's landmark publication on the topic, to ensure rigor and trustworthiness across our study.⁽⁸⁵⁾ We triangulated by using two types of informants, patients and caregivers. We actively encouraged honesty from our participants, but also passively by promoting opportunities to refuse to participate, making clear their right to withdraw, and emphasizing the interviewer's independent status vis-à-vis their care. We assessed contextual factors (e.g., the investigators' backgrounds, personal experiences, and interests) and how they could have influenced the study conduct and outcomes, examining these issues by holding frequent debriefings and by maintaining internal, reflective commentary. Conjointly, we also welcomed outside scrutiny by holding a focus group at the study site where clinicians were presented results and findings. We had also held a separate meeting with primary care clinician researchers. Both meetings enhanced and helped validate our interpretation.

Ethics

The study was approved by the research ethics committee of the Jewish General Hospital, Montreal, and is in compliance with all relevant federal guidelines and institutional policies.

RESULTS

Quantitative Results

The 15 recruited patients (Figure 1) 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 MMSE score of 27.0 (2.4, 21–30) and mean MoCA of 22.7 (3.4, 15–27). In fact, of all patients we tried to recruit, just one patient was excluded because their disease was evaluated to be too severe. Patients included in our study reported

“memory”, “physical health”, “money/budgeting” as their main needs, and received both informal and formal help to meet most needs.

The 15 recruited caregivers were aged 72.3 years old (12.5, 41–90); 12 were women. Note that all caregivers in our study satisfied the “stronger” inclusion criterion of “time spent together with the patient” and that, in fact, all caregivers satisfied more than one inclusion criterion. The caregivers in our study 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 were older, had a longer onset of memory symptoms, worse cognition, and more behavioural symptoms (Table 1).

Importantly, the foreign-born patients reported more needs and a lower quality of life (Tables 1 and 2). The two groups expressed different needs: only foreign-born patients reported needs in “eyesight, hearing, communication”, “mobility/falls”, “looking after the home” and “company”.

The nine foreign-born caregivers were younger than their six Canadian-born peers. The former reported more

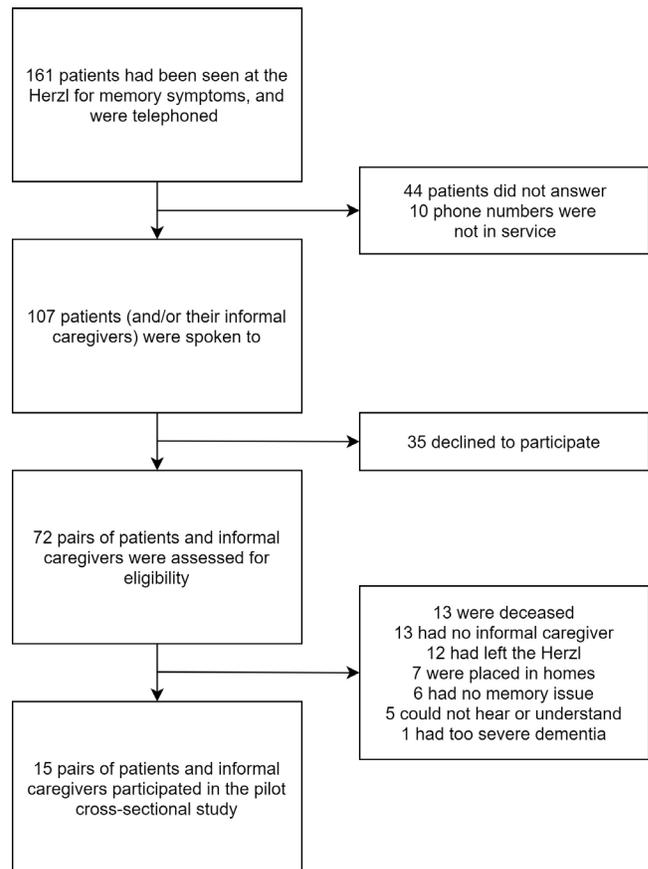


FIGURE 1. Recruitment of study participants at the Herzl Family Practice Centre

YANG: CULTURAL DIVERSITY OF DEMENTIA PATIENTS

TABLE 1.
Characteristics of Canadian-born and foreign-born patients (Canadian n=5, foreign n=10)

	<i>Canadian Born</i>	<i>Foreign Born</i>
Age (mean, SD, range)	74.80 (12.26, 61–91)	77.40 (7.86, 61–90)
Sex, male (number, %)	3 (60.00%)	7 (70.00%)
<i>Highest Level of Education Received (number, %)</i>		
Below high school	0	3 (30.00%)
High school or apprenticeship	4 (80.00%)	4 (40.00%)
College, CEGEP, university and above	1 (20.00%)	3 (30.00%)
<i>Labor Force Status and Work Activity (number, %)</i>		
Retired	5 (100.00%)	9 (90.00%)
Working full-time	0	1 (10.00%)
<i>Relationship Between Patient and Caregiver (number, %)</i>		
Couple	5 (100.00%)	9 (90.00%)
Parent-child	0	1 (10.00%)
<i>Ethnocultural Characteristics</i>		
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	3 (30.00%)
<i>Knowledge of Official Languages of Canada (French And English) and Other Languages (number, %)</i>		
Unilingual, speaks one official language	2 (40.00%)	6 (60.00%)
speaks only French	2 (40.00%)	2 (20.00%)
speaks only English	0	4 (40.00%)
Bilingual, speaks French and English	3 (60.00%)	4 (40.00%)
Speaks foreign language(s) natively	1 (20.00%)	5 (50.00%)
<i>Spiritual Beliefs (number, %)</i>		
Agnosticism or atheism	2 (40.00%)	3 (30.00%)
Christian	2 (40.00%)	4 (40.00%)
Judaism	1 (20.00%)	3 (30.00%)
<i>Patient’s Memory Issues (mean, SD, range)</i>		
Self-reported onset in years	3.00 (1.22, 2-5)	3.10 (2.33, 1-9)
MMSE	28.20 (1.10, 27-30)	26.40 (2.67, 21-30)
MoCA	25.60 (1.52, 24-27)	21.20 (3.12, 15-25)
Prescribed cholinesterase inhibitor (number, %)	1 (20.00%)	4 (40.00%)
<i>NPI (mean, SD, range)</i>		
12 item NPI score	4.80 (8.58, 0-20)	6.90 (7.52, 0-20)
<i>Patient’s Health (mean, SD, range)</i>		
Number of comorbidities	5.20 (2.05, 2-7)	4.10 (2.38, 1-8)
Number of active medications	10.00 (2.00, 7-12)	8.10 (2.23, 5-11)
<i>QOL-AD (mean, SD, range)</i>		
Scored by patient	42.20 (2.86, 39-46)	37.10 (5.09, 28-43)
Scored by caregiver	37.00 (10.37, 20-48)	34.90 (7.53, 19-47)

TABLE 2.
Needs of Canadian-born and foreign-born patients (Canadian n=5, foreign n=10)

<i>CANE</i>	<i>Canadian Born</i>	<i>Foreign Born</i>
Patient-reported met needs (mean, SD, range)	3.20 (1.10, 2-5)	4.00 (2.05, 2-8)
Patient-reported unmet needs (mean, SD, range)	0.60 (0.89, 0-2)	0.50 (1.27, 0-4)
Patient-reported total needs (mean, SD, range)	3.80 (1.30, 2-5)	4.50 (2.01, 2-8)

stress associated with their patient’s behavioural symptoms (Table 3).

Foreign-born caregivers also reported more problems (and different problems) and more needs (and different needs) for services (Table 4). Only foreign-born caregivers encountered “legal issues”, “communication problems and conflicts with the patient”, “burden by behavioural problems of the patient” and “social isolation and conflicts within the family”, which led them to want “temporary supervision of the patient at home”, “care for the patient in a day centre”, “respite care”, “self-help group for family members”, and help “initiating to become a legal administrator”.

Qualitative Results

Six pairs of patients and caregivers (equal number of Canadian born vs. foreign born individuals) with different need profiles were interviewed. No clear difference was noted between the two groups, except that foreign born individuals drew from their past experiences abroad to understand and appreciate the healthcare system and services they are presently a part of. Recurring themes had emerged falling into three broad categories: (1) attitudes towards the illness, (2) perceptions of health care, and (3) cultural dimension of dementia management.

The first category, patients’ and caregivers’ overarching attitudes towards the illness, highlighted ideas that arose throughout the interview, colouring the entirety of a participant’s account. One important theme was “preparedness”. Interviewees showed clear motivation and proactiveness in seeking care, wanting to think and plan ahead, but often saw that their family physician was not enough to answer all their questions and meet all their needs. Another central theme was “family”, which was identified as a key resource to all patients in coping with the illness and navigating health care, whether it was their spouse or a child, from planning visits to the health professional to the travelling itself, and the relaying and understanding of clinical information. Throughout the interviews, there was an “unwillingness to complain”. Despite having valid criticisms or suggestions for improvement, many participants accentuate these with remarks of gratitude for their current professionals and do not want to be perceived as complainers.

Secondly, patients and caregivers perceived their health care thusly. A dominant feeling amongst participants was an appreciation for the “family physician’s expertise, but they are often rushed in time” to jump to the next patient. Some patients felt that not having enough doctors was an inevitable

reality, while others felt politics was to blame. Interviewees held “ambivalent views towards resident family physicians”. On one hand, many did not consider residents as physicians, wanting to consult a more senior, experienced practitioner. Being registered to a resident was sometimes also perceived as disruptive to their continuity of care. On the other hand, they remained generally confident in the quality of care provided by residents because of the staff physician’s supervision. There was a general “enthusiasm towards the case manager and case management”. Many recalled their visit with the case manger positively. There are also a minority of patients, as well as caregivers, who did not remember meeting the case manager; these individuals nevertheless expressed interest in case management as an additional resource that may be able to answer more of their questions, alleviating pressure from the family physician.

Thirdly, the theme of the cultural dimension of dementia management in primary care emerged from the interviews. Importantly, all participants identified that they were seen in “cultural incident-free environments”. There was no report of misunderstanding, frustration or conflict because of race, ethnicity, nationality, language, beliefs, values, and traditions. The interviewees were “aware of diversity among human beings”, as they were “aware of oneself”, recognizing themselves as belonging to a distinct ethnicity, and they were “aware of the other”, recognizing that their loved one or a health professional may not belong to the same ethnicity and may not share the same culture. All participants expressed that seeing a health professional of their own ethnic origins would not change their health-care experience, for better or for worse. Being a good physician, in their mind, had nothing to do with the physician’s ethnicity. Patients and caregivers were “disinterested in the idea of ethnic matching”. From a different light, this could be regarded as the patients’ and caregivers’ “non-judgmental openness for all individuals”.

DISCUSSION

Discussion of Quantitative Results

We described the great cultural heterogeneity of our study participants, and we illustrated differences in patient and caregiver needs for both those born in Canada and born outside Canada.

CANE and CNA-D projected vivid pictures of the patients and caregivers needs and problems: case management met most patient needs, but not caregiver needs. That said, it

TABLE 3.
 Characteristics of Canadian-born and foreign-born caregivers (Canadian n=6, foreign n=9)

	<i>Canadian Born</i>	<i>Foreign Born</i>
Age (mean, SD, range)	75.50 (13.32, 1-5)	70.22 (12.25, 41-83)
Sex, male (number, %)	1 (16.67%)	2 (22.22%)
<i>Highest Level of Education Received (number, %)</i>		
Below high school	1 (16.67%)	3 (33.33%)
High school or apprenticeship	1 (16.67%)	3 (33.33%)
College, CEGEP, university and above	4 (66.67%)	3 (33.33%)
<i>Labor Force Status and Work Activity (number, %)</i>		
Retired	4 (66.67%)	7 (77.78%)
Working part-time	0	1 (11.11%)
Working full-time	2 (33.33%)	1 (11.11%)
<i>Relationship Between Patient and Caregiver (number, %)</i>		
Couple	6 (100.00%)	8 (88.89%)
Parent-child	0	1 (11.11%)
<i>Ethnocultural Characteristics</i>		
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	3 (33.33%)
<i>Knowledge of Official Languages of Canada (French And English) and Other Languages (number, %)</i>		
Unilingual, speaks one official language	2 (33.33%)	6 (66.67%)
speaks only French	0	3 (33.33%)
speaks only English	2 (33.33%)	3 (33.33%)
Bilingual, speaks French and English	4 (66.67%)	3 (33.33%)
Speaks foreign language(s) natively	1 (16.67%)	6 (66.67%)
<i>Spiritual Beliefs (number, %)</i>		
Agnostic or atheist	3 (50.00%)	1 (11.11%)
Christian	3 (50.00%)	5 (55.56%)
Jewish	0	3 (33.33%)
<i>NPI (mean, SD, range)</i>		
12 item caregiver distress score	0.83 (1.41, 0-3)	5.33 (6.28, 0-20)

is plausible that caregiver needs would be greater without case management. Overall, the number of needs and problems was small compared to existing reports in the literature.^(70,86,87) In reality, a single need, regardless of its statistical significance, may have a real and disproportionate impact on a person’s quality of life. From a different perspective, even a small number of needs can be acted upon and lead to change in practice and quality of care; for instance, following the presentation of our results to clinicians at the study site, one immediate reaction was for the clinic to more readily distribute printed information material on dementia and related resources.

The quantitative differences observed between Canadian-born vs. foreign-born individuals were reminiscent of ethnic

disparities reported elsewhere in the world.^(15-19,31-33,38-40,88) Our study innovates by systematically examining the needs of patients and caregivers of different ethnic backgrounds. However, in our case, such disparities may be explained in part by the presence of confounders. We also note great cultural heterogeneity within the two groups. Though inconclusive, our results merit further investigation.

Discussion of Qualitative Results

Among our participants, being born and raised in vs. outside Canada did not seem consequential in their experiences with dementia through primary care case management. Indeed, patients and caregivers born in Canada and elsewhere told

TABLE 4.
Problems and needs of Canadian-born and foreign-born caregivers (Canadian n=6, foreign n=9)

<i>CNA-D</i>	<i>Canadian Born</i>	<i>Foreign Born</i>
Number of moderate or serious problems (mean, SD, range)	1.50 (2.07, 0-5)	2.89 (2.37, 0-7)
Met needs (mean, SD, range)	0.67 (0.89, 0-2)	0.89 (0.78, 0-2)
Unmet needs (mean, SD, range)	1.83 (2.99, 0-7)	2.78 (3.23, 0-10)

similar stories and held similar positions about their experiences with dementia through primary care. They all perceived they received care from competent professionals and reported no cultural incidents, but they had unanswered questions that could be better addressed with the case manager. The role of the latter was less well-remembered and explained by study participants, compared to their understanding of the physician’s role in their care; we can hypothesize that the case manager is a less known figure in the public consciousness, is a relatively new addition with wider variation of responsibilities in primary care compared to that of the physician, and has, in most cases, been acquainted with individual service users for a shorter period of time, in comparison the family physician who often has known their patient for far longer.

Importantly, patients and caregivers themselves showed cultural competence in face of their health professionals’ cultural diversity. Though we attempted in applying Jirwe’s framework of cultural competency as it was intended, only a few of its subthemes could be used. The answers we obtained were from service users, while cultural competency is mostly defined by Jirwe *et al.*⁽⁸⁴⁾ as an introspective, proactive process of the service provider to learn, adapt, and care around cultural diversity. Therefore, we only go as far to describe our participants’ care as being “free of cultural incidents” rather than truly culturally competent.

However, as evident in qualitative results, we applied Jirwe’s framework more successfully to the patients and caregivers themselves. Though some elements are specific to professional health care, many subthemes and themes emerged from the patient and caregiver interviews. We can reasonably conclude that the service users themselves are culturally competent, not in providing care but in receiving care. This may be a key part of the answer on why their experiences have been “free of cultural incidents”: dementia care is a two-way exchange between service users and providers. While institutions are presently overwhelmingly focused on the cultural training of health professionals, we can envision outreach work in ethnic communities and promotion of cultural knowledge related to health with high risk groups of potential patients, for example, refugees.

Mixed Methods Integration

The quantitative differences in needs of Canadian-born vs. foreign-born patients and caregivers were inconclusive, though the possibility of true differences existing could not be ruled out either. At the same time, the two groups of participants share similar attitudes, views, and experiences in

their living with a deteriorating memory and frequenting the health-care system. If true differences of needs between the two groups did exist, they cannot be explained or clearly attributed to their different ethnocultural origins, at least within our sample of participants.

Rather than separate quantitative and qualitative studies, conducting a mixed methods study provided an opportunity to clarify and enrich quantitative results, completing a more detailed and nuanced understanding of the same study population at their current stage of life and illness.

This present study is a useful exercise; we argue that mixed methods is particularly suited to explore the complex reality of dementia, from its multidisciplinary care strategies to the patient’s and family’s intricate and diverse experiences with the disease, and the health and psychosocial services provided. Standardized, quantitative tools may not fully capture or explain strengths or gaps of dementia care; qualitative methods serve to complement or challenge quantitative results, or uncover new issues entirely. In brief, one main contribution of the present study was to illustrate the pertinence of mixed methods to the growing area of studies of dementia care and services, as well as the cultural dimension therein.

Limitations

The population was difficult to recruit, resulting in a small sample that was not representative of the Canadian patient population. Though the study site’s dementia patient population was comparable in sex and age to the national averages, our sample was noticeably younger and more male, suggestive of selection bias.^(89,90) For instance, it is possible that older dyads, affected by more severe disease, could be less available to participate in research; the nature of our study in particular necessitates hours-long commitment. We tried to mitigate this by offering home visits and, in fact, a great majority of data collection (all but one dyad) was done this way. Nevertheless, overall, we consider quantitative results to be hypothesis-generating.

However, our sample, though small, was culturally diverse enough vis-à-vis Montrealers overall.^(13,14) That said, our analysis reduced the ethnic richness of our sample into two groups, though we provided statistical description of the heterogeneity therein. We also remain cautious about generalizability or transferability because of the uniquely diverse context of study.

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.

One strength is how, in many instances, the mixed methods design allowed qualitative findings to confirm quantitative results. For example, the theme of “preparedness” reinforces the caregiver’s problems of “lack of information” and “concern about the patient’s future”.

Future studies should aim to capture more cultural groups, and include dementia patients living alone with no identifiable caregiver.

CONCLUSION

The pilot study served as an entry point to explore cultural diversity in dementia care. Quantitative differences between Canadian- vs. foreign-born individuals were hypothesis-generating, but quantitative results served to reflect upon and improve the care of our patient population. These two groups of patients and caregivers also told similar stories and held similar positions about their experiences receiving health care: whether they were born here or abroad, they enjoyed a cultural incident-free milieu with professionals perceived as generally capable, but hoped to have more of their questions addressed and perhaps the case manager would be the right person. Crucially, in our interviews, patients and caregivers displayed a degree of cultural competence when faced with the cultural diversity of their health professionals. This pilot study will drive a larger research project to achieve a more holistic understanding of dementia management in primary care. 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.

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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