

# We are IntechOpen, the world's leading publisher of Open Access books Built by scientists, for scientists

**4,800**

Open access books available

**122,000**

International authors and editors

**135M**

Downloads

Our authors are among the

**154**

Countries delivered to

**TOP 1%**

most cited scientists

**12.2%**

Contributors from top 500 universities



**WEB OF SCIENCE™**

Selection of our books indexed in the Book Citation Index  
in Web of Science™ Core Collection (BKCI)

Interested in publishing with us?  
Contact [book.department@intechopen.com](mailto:book.department@intechopen.com)

Numbers displayed above are based on latest data collected.

For more information visit [www.intechopen.com](http://www.intechopen.com)



## Chapter

# An Examination of Factors Influencing Equitable Access to Dementia Care and Support Programs among Migrants and Refugees Living with Dementia: A Literature Review

*Winnie Sun, Srija Biswas, Michelle Dacanay and Ping Zou*

## Abstract

Canada is working on improving the diagnosis and treatment of Canadians with cognitive impairment and promoting living well with dementia. Despite the availability of support network, Canadians living with dementia are identified to commonly experience social isolation and exclusion. This issue is particularly significant among migrants and refugees, for whom access to dementia care and support programs are found to be significantly less than the non-migrated Canadians. The purpose of this critical analysis is to examine the existing literature related to the sociocultural factors that contribute to the access of dementia care and support programs by persons with dementia. Specifically, a literature review was conducted to examine the barriers and facilitating factors that influence equitable access to dementia care and support programs among migrants and refugees. A thematic analysis was conducted to identify the following four major themes: (1) stigma, (2) culturally preferred coping strategies, (3) misconceptions regarding aging and dementia, and (4) language barriers.. This review identifies the need for future research to explore the key barriers faced by migrants and refugees with dementia in accessing timely and appropriate dementia care and support programs, as well as developing equitable programs and culturally sensitive services that adequately address their needs.

**Keywords:** literature review, migrants, immigrants, refugees, sociocultural barriers, access, dementia care

## 1. Introduction

### 1.1 Background

Dementia has been identified as one of the leading issues concerning people over the age of 65. A number of Canadians aged 40 and older living with Alzheimer's disease and other forms of dementia are expected to increase over time. In fact, this

increase will be from about 395,000 in 2016 to 674,000 in 2031 [1]. In the Statistics Canada 2016 report, it estimated that 35.6 million global citizens were living with dementia and that the number is expected to double within the next 20 years [2]. When diagnosing an individual with dementia, physicians refer to the Diagnostic Manual of Mental Disorders (DSM) as a guide when determining whether the individual shows progressive tendencies of dementia [3]. The manual that is currently in practice is the DSM-5, which classifies dementia as a neurocognitive disorder. Generally, dementia is an umbrella term that encompasses a variety of symptoms related to the decline of cognitive function, which influences a person's ability to execute everyday activities [3]. In order to be diagnosed with dementia, one must meet certain criteria listed in the DSM-5 when determining major neurocognitive disorders such as (a) showing evidence of significant mental decline that interferes with mundane daily routines or (b) for milder cases showing signs of modest cognitive decline with only little interference of daily active living [4]. The DSM-5 criteria for tendencies of dementia include (1) cognitive changes, including new forgetfulness and difficulty finding words; (2) psychiatric symptoms, such as withdrawal or apathy, depression, and anxiety; (3) personality changes, such as blunting and disinterest and social withdrawal; (4) problem behaviors, such as wandering, agitation, and restlessness; and (5) changes in day-to-day functioning, including difficulty driving, getting lost, neglecting self-care, and difficulty handling money [3].

There are different forms of dementia due to variances in the distinct expression of symptoms in addition to structural brain abnormalities. One of the most common forms of dementia is Alzheimer's disease, followed closely then by vascular dementia [5]. Other known types of dementia include dementia with Lewy bodies (DLB) and frontotemporal dementia. Moreover, impaired mental functions that arise due to the neurodegenerative disease include memory, language and communication, judgment and reasoning, and attention span [3]. Even emotional control and social behavior and motivation are altered and may deteriorate as the disease progresses. Rates of dementia, including Alzheimer's disease and other forms of illness, are projected to increase continuously and double every 20 years [6]. It is estimated that in 2010, over 35 million people worldwide were living with dementia [7]. Dementia and Alzheimer's disease are considered as an abnormal process of aging. Common symptomology includes frequent memory loss and finding family members and friends unrecognizable [8]. It is believed that people first experience an asymptomatic period where neurodegenerative changes occur in the brain, while cognitive abilities remain stable. This preliminary phase occurs for a long duration and is followed by the progressive cognitive decline and the eventual, late-stage development of dementia [9].

Living with dementia means coping with the progressive loss of physical and mental abilities. It can have an overwhelming negative impact on the individual and those around them by progressively altering every part of their life until the individual becomes completely dependent on either their loved ones, paid caregivers, or a combination of both. Living with dementia imposes a large physical health, mental health, and economic burden on the patients, informal caregivers, and family member [10]. It can affect the patient in many ways starting from increased dependency on caregivers for daily life activities, inability to be engaged in activities that they were previously able to, leading to frustration and short-temperedness, depression and anxiety, confusion, and fear [11]. Regardless of the availability of a strong support network, people with dementia have been identified to commonly face isolation, loneliness, and social exclusion. In order to improve the quality of life of individuals living with dementia and their caregivers, Canada is implementing national strategies and community level actions to improve and

strengthen their support network and with the aim of promoting living well with dementia [12]. Cultural diversity is one of the key characteristics that defines the current Canadian demographic shift. It is estimated that by 2031, visible minorities from multicultural backgrounds among whom majority have lived in Canada for less than 15 years will make up approximately 63% of the population in Toronto, the largest city in Canada [13]. Increasing the number of migrants will lead to an increasing number of persons with dementia from various cultural backgrounds. As the dementia community possesses increased cultural diversity, it is crucial to identify the relationship between sociocultural factors and access to support programs aimed at promoting living well with dementia [14, 15]. Similarly, refugee populations of every age group living in a foreign country often suffer from various challenges including language difficulties, acculturative stress, loneliness, and societal prejudice, leading to a depleted social network and barriers to accessing necessary services and supports [4]. In particular, a reduced level of participation is observed in dementia care and support programs among immigrants and refugees compared to their nonimmigrant counterparts [15]. There is a need to increase our understanding about the unique needs of the immigrants and refugees with dementia that would promote their timely and appropriate access to dementia support services in the community.

## **1.2 Objective**

The purpose of this chapter is to review the existing literature related to the persons living with dementia who have migrated as a refugee or immigrant and to explore the sociocultural factors that contribute to the access to dementia care and support programs among these vulnerable populations. Our literature review will place special emphasis on the Southeast Asian population because the number of people living with dementia in the Asia Pacific region will triple between now and year 2050 with Alzheimer's disease being projected to rise by 300% among Southeast Asians, the highest projected rise among other ethnic groups [31].

This literature review aims at:

1. identifying the sociocultural factors influencing access to and participation in dementia care and support programs among migrants and refugees, with emphasis on Southeast Asian populations;
2. exploring knowledge gaps in the existing literature to identify further research opportunities in relation to improving access to dementia care and support programs for migrant and refugee populations.

## **2. Method**

In order to address the above objectives, a literature review was conducted using a predetermined inclusion-exclusion criteria and search strategy as outlined below.

### **2.1 Inclusion and exclusion criteria**

The search strategy for the literature review included journal articles and research papers that were published until May 2017. A preliminary search was conducted on this topic to determine the scope of the existing literature, which has revealed a lack of published research in the field of dementia care for migrants and refugees. As a result, no specific boundary was set on the date range of publication,

and any relevant article was included in the literature review regardless of its publication date. Articles that were published in English were only included in the search. The keywords used for the literature search were “migrants,” “cultural barrier,” and “dementia support program,” and these search terms were used to explore the cultural barriers faced by migrants in order to access dementia support programs. “Immigrants,” “refugees,” and “new comers” were also used within the keyword set as migrated population contains immigrants, newcomers, and refugee subgroups. Both “dementia” and “Alzheimer” research related to support programs and care designed for dementia and Alzheimer’s disease are often comparable in nature and content, and frequently these two words were used interchangeably. Research regarding both support programs and care services are included in the literature review to encompass all types of barriers faced in regard to access to dementia care and support programs. Research conducted on populations including persons living with dementia, informal and formal caregivers (such as nurses, personal support workers, and other service providers), and dementia program facilitators and coordinators were included in the literature review. Research about barriers to equitable access among certain subgroups such as indigenous people was excluded from this review. Despite the diverse cultural background of indigenous population, this subgroup is not considered migrants.

## **2.2 Search strategy and data analysis**

An extensive search of the literature was performed using the University of Ontario Institute of Technology (UOIT) library databases, including the PubMed databases and Wiley Library. The search strategy was consistent for every database and was based on the predetermined set of inclusion and exclusion criteria. Only full-text papers published in peer-reviewed journals and proceedings were selected for further review. Editorials, letters, and conceptual papers were excluded. All papers that addressed the keywords and search terms that were relevant to the research topic of interest were retrieved, regardless of their study design.

A total of 4451 research publications resulted from the keyword search from both databases which included peer-reviewed journal articles, eBooks/books, dissertations/thesis, and book chapters. Abstracts that were identified to be relevant to the research question were kept, and full-text papers were retrieved for further review. In the absence of an abstract, full-text papers were retrieved and reviewed for prospective inclusion. Reference lists of selected papers were examined to identify other relevant articles. There were a total of 15 articles included in the final data analysis using a thematic analysis method based on its relevance and the scope of research for data extraction purposes. The data extraction details about these 15 articles are presented in Appendix A. The findings were analyzed and synthesized to identify common themes, methodologies, and research gaps. In addition to the scholarly literature, gray literature found in credible websites were used to obtain information and findings such as statistical data, current approaches, and recommendations from the Alzheimer Society of Canada, Alzheimer’s Society of the United Kingdom, and Statistics Canada.

## **3. Results and discussion**

### **3.1 Key findings from literature review**

Analysis of the existing literature that explored the underlying factors associated with the access to dementia support programs among migrant and refugee

populations from diverse cultural backgrounds has led to the emergence of the following four themes, which are discussed below.

### *3.1.1 Stigma associated with dementia*

The most common and impactful factor associated with the access to dementia support programs among migrants was stigma. The Alzheimer's Society of Ireland (2008) reported on two types of stigma, one as external, indicating stigma toward the person by community members, and the other as internal, indicating perceived feelings of shame about themselves that they are "less of a person" because of the symptoms of dementia [16]. Stigma affects the individual with dementia, which includes but is not limited to willingness to seek diagnosis and to seek support once diagnosed and a lack of willingness to participate in research [16]. In some cases, stigma about mental health impairments such as dementia was so deeply rooted that individuals and family members would deny to "recognize the illness" [17]. Data obtained from persons with dementia and family members reported that stigma often prevented them from seeking necessary information or support as "people would gossip about you if something went wrong" and "people don't want to get branded as odd or weird" [17].

In South Asian culture, mental health impairments including dementia are associated with perceived stigma toward the individual and their family members. A great deal of stigma appears to be associated with mental illness in such cultures where open discussion of a relative's mental health issues could cause the family to be stigmatized, with a reduced social standing that could affect later generations, such as interfering with marriage arrangements [15]. South Asian migrants thus appeared to be engaged in "concealment" as a mechanism to protect the reputation of the person with dementia and reputation of their family [15, 18]. The most common explanation for not using any support services among informal caregivers was that seeking support from outside agencies "put an already precarious balance between shame and inner pride in jeopardy" [18]. In Eastern European cultures, stigma associated with dementia also reinforces the tendency to "keep it in the family" instead of seeking support [18] as "going public" about having a family member with dementia is linked with a perceived fear of inviting condemnation from others in the community [18]. This reinforces the behavior of informal caregivers around providing support alone instead of seeking help from social and community support networks.

Persons with dementia were also identified to be vulnerable to experience stigma associated with chronic and severe mental illness, such as schizophrenia, because they shared a set of similar behavioral symptoms including depression, delusions, hallucinations, and agitation. For instance, researchers from Hong Kong outlined the social consequences of stigma associated with mental illness among Asian culture [19]. Lee and colleagues identified that concealment and anticipated stigmatization had a significant impact on non-compliance with care-seeking behavior. Persons with dementia and their family members attempted to hide their diagnosis from the community and forbid further interaction between the person with the illness and community members in the attempt to hide any shameful incidence [19]. Among Asian Americans such as Chinese and Vietnamese, shame and "loss of face" were identified to contribute to stigmatization associated with dementia [20] where shame was triggered by public display of abnormal behavior. Concealment was adopted to deflect such situations [21], resulting in delays and nonadherence to acquiring external care and support.

### *3.1.2 Culturally preferred coping strategies*

Culturally preferred coping strategies were most prominent in South Asian immigrants and refugees where this specific characteristic reflected the ascribed stigma as discussed above. In fact, religion and culturally preferred coping strategies were identified to be particularly important within South Asian communities, opposed to the value of understanding symptom management and access to available resources, which is observed more in other ethnic minority groups [15]. South Asian subgroups appear to place high value on family where providing care for a family member is associated with the perception of responsibility toward their loved ones. In some South Asian cultures, “caring” was identified to be a religious obligation regardless of the religion, where caring was perceived as “duty” or a way of “gaining blessings” or “repaying” the person with dementia for previous acts of kindness [18]. Thus, South Asians have been reported to prefer providing care for a family member with a mental illness rather than seeking medical care, social care, or community support and assistance [15], leading to reduced engagement in dementia support programs or other social/medical care supports. Some South Asian subgroups were observed to use “faith” as an alternative coping strategy where faith is perceived to be associated with enhancing mental resilience and alleviation of stress experienced by persons with mental illnesses such as dementia and their caregivers [15]. Meditation and prayers were identified as tools used in religiously preferred coping strategies. The ideology of “caring” was also observed among Asian American migrants in addition to South Asian migrants. A study conducted on Korean immigrants with dementia revealed a concept of “Korean way of thinking,” where caring for ill elderly in the family is considered a responsibility and is associated with “saving face” [22].

The concept of “acculturation” also appears as an important concept in terms of implications for support services among migrants. Acculturation varied depending on the length of stay in a migrated country and historical time of migration [22, 23]. Adoption of a foreign culture appears to be a selective process where fundamental values and beliefs appear to stay unchanged after immigration [22]. A study conducted on Korean immigrants in America indicated that those who migrated recently are more “Americanized” than those that migrated a long time ago and tend to preserve their traditional beliefs [22]. Failure to adopt the foreign culture can lead to the preservation of conventional norms and methods of practice in one’s culture when dealing with chronic diseases, such as dementia.

### *3.1.3 Misconception regarding aging and Dementia*

“Normalization” of functional and cognitive decline among older adult populations is observed to be a vastly shared belief in many cultures. Studies reveal that populations from ethnic minorities are less likely to recognize symptoms of dementia as an illness than Caucasian individuals, perceiving such symptoms as part of the aging process [24]. Normalization is observed among Asians, African-Caribbeans, and Hispanic Americans where dementia symptoms such as memory loss, disorientation, and loss of functional abilities were recognized but not conceptualized as an illness [25]. In Asian culture, dementia related to changes such as confusion is often normalized and expected as part of the aging process [20]. A majority of the common symptoms of dementia are interpreted as “age-related cognitive and functional change.” Symptoms such as “memory failure” or “confusion” are considered normal among “very old” members of the family. Interviews conducted on subgroups originating from Chinese and Vietnamese cultures identified a culturally shaped metaphor that emphasized holism and the inevitability of

deterioration in dementia [20], reinforcing the lack of understanding regarding the necessity of accessing dementia support programs.

Evidence from South Asian subgroups residing in England has identified that people from South Asian culture may recognize the symptoms associated with dementia but not conceptualize these as part of an illness even when they are severe [17], leading to the idea that individual and family efforts are sufficient to ameliorate dementia-related symptoms. Research conducted on South Asian families recognizes a generalized picture of aging that exists in South Asian culture where it is perceived that aging changes older people into an “intolerant and worrying” group and aging makes people “difficult and angry” [17]. Many dementia-related symptoms such as confusion, becoming quiet and sad, feelings of isolation and loneliness, and other mental health impairments are often viewed as “negative” aspects of normal aging [17, 24] in South Asian families. This leads to the conceptualization of not viewing dementia as an illness and therefore creating a barrier to accessing the external resources that support living well with dementia.

Another common misconception that exists in many different cultures is the lack of understanding on the causation of dementia. Dementia is often perceived as a mental illness by certain South Asian groups who are especially sensitive to traditional, religious, and spiritual explanations of the nature and causation of dementia [18]. Many South Asian cultures lack a defined vocabulary to interpret the word “dementia”; thus cases of dementia are often classified as a mental illness [15, 18]. Many individuals from South Asian cultures residing in the United Kingdom classify dementia as “madness” as the meaning of dementia is nonexistent in the vocabulary of South Asian languages [23]. In such cases, family members and the community at large frequently use concealment for avoiding rejection, which acts as an obstacle to accessing dementia support programs.

### *3.1.4 Language barrier*

Language barrier was a significant factor leading to the reduced access to dementia support programs and services. Current literature revealed that migrants and refugees who do not speak the language of the host country might be at a greater disadvantage in accessing the health-care system [23], making the individual with a lack of language proficiency more vulnerable to inequitable access to dementia support services. Language difficulties often appear in Alzheimer’s disease and other neurodegenerative dementias with word-finding difficulties, decreased verbal fluency, or difficulties with naming and comprehension, which are particularly prominent among bilingual individuals [26]. Older bilinguals often revert to a single language despite a lifetime of dual language use, losing the ability to speak the second language [26]. This issue is particularly prominent among migrants and refugees with dementia who lose their ability to speak their second languages, which is often the language of their host country, leading to difficulty in communicating with the health-care professionals and service providers [27]. Bilingual individuals with dementia are frequently observed to be inclined to asymmetrical language impairment with preferential preservation and the use of the first acquired language [28], which can be inferred among individuals that have migrated to a foreign country that speaks a different language than one’s country of emigration. Moreover, recently learned information is retained the least in the case of dementia, whereas information and memory that are more remote are often relatively preserved, leading to a regression toward the predominant use of the language learnt earlier in life or the first language [26, 28].

Evidence obtained from the study of immigrants in Sweden suggested that immigrants with dementia noticeably preferred music and television programs that



had more familiarity, such as programs in their native language [27]. They were also more likely to participate and engage in dementia support programs and services where they could communicate in their native language [23, 26]. Research evidence from Korean Americans with dementia suggested that treatment and intervention programs designed to promote living well with dementia were observed to be more effective when using a familiar language or the native language of the individual [29]. Inability to communicate well in the language of the program due to losing the ability to speak one's second language has been identified as one of the leading issues among individuals with dementia, particularly among those who have migrated from a foreign country with a different language than the host country.

#### **4. Implications and conclusion**

The literature review revealed that the most common underlying factors that influence reduced participation and access to dementia care and support programs among immigrant and refugee populations were stigma, culturally preferred coping strategies, misconceptions regarding aging and dementia, and language barriers. In particular, coping strategies were significantly influenced by the stigma associated with dementia as most cultures preferred concealment to avoid being negatively labeled in the community [15]. Misconceptions regarding aging and normalization of dementia are a commonly observed phenomenon among the majority of the well-known cultures in Europe and North America [16].

Research conducted on sociocultural factors and access to dementia care is often conducted among caregivers as opposed to the persons with dementia themselves, where conclusions made regarding the needs of persons with dementia were obtained indirectly from their care partners, formal and informal caregivers, and service providers. The rationale behind this approach was largely due to the difficulty of conducting research on persons with dementia as a result of their levels of cognitive impairment. In particular, there is a lack of empirical evidence obtained directly from persons living with dementia among migrated and refugee populations. Moreover, majority of the existing research about dementia care were conducted in certain countries such as in Europe and Australia. Findings from North American settings focused mainly on the American immigrants with dementia. There is a lack of research about the influencing sociocultural factors and access to dementia care/support programs among Canadian migrants. Most research examined barriers to access related to geographical location, economic status, educational level, and knowledge of dementia/care. There is a lack of empirical evidence on the impact of how stigma, cultural background, and language influence appropriate access to dementia support programs among migrants. There is also a lack of research that focuses on identifying the existing needs among immigrant populations with dementia in regard to their access to dementia care. These findings highlight the need to conduct further research on Canadian immigrants/refugees with dementia to further explore the key barriers faced by these populations in regard to accessing dementia care and support programs, as well as to identify the facilitating factors that meet the unique needs of Canadian migrants to promote living well with dementia.

Currently there are 564,000 Canadians living with dementia, and this number is doubling every 20 years [12, 30]. In addition to the rising number of persons with dementia, there has been a shift in the population triangle of Canada, with an increasing number of the population reaching the age 65 and up, which is the most vulnerable stage of life to develop dementia [30]. In particular, migratory increase has been identified as the major driving force of population growth in Canada,

which indicates a change in the composition of the population with an increased cultural diversity [31]. As a result, it is imperative to increase our understanding of the influence of sociocultural factors in relation to equitable access of dementia care and support programs among the Canadian migrants. This knowledge is vital to the future transformation of the existing programs and services, shaping them to be more culturally inclusive for the marginalized, migrated, and refugee populations in Canada.

### Competing interests

The authors declare that they have no competing interests.

### Author's contributions

All authors provided input into the development of the literature review and have read and approved this manuscript.

### Funding

The authors declare that there is no funding support for this project.

### Ethical approval and consent to participate

Not applicable.

## Appendix A. Summary of research studies included in the literature review

Author (date)	Study purpose	Study design	Summary of key findings
Swaffer K (2014)	Exploring the language being used to represent people with dementia, and the presence of stigma to identify if presence of stigma toward people with dementia aggravates the stigma or prevents the timely translation of good research into better practice	Robust literature review	<ul style="list-style-type: none"><li>• Stigma affects several aspects when considering dementia, including the person's willingness to seek diagnosis, to seek support once diagnosed, and a lack of willingness to participate in research</li><li>• Caregiver stigma has been explored often but very little on the stigma as experienced directly by people with dementia</li></ul>

Author (date)	Study purpose	Study design	Summary of key findings
Fontaine et al. (2007)	Explore the perceptions of aging, dementia, and aging-associated mental health difficulties among British people of Punjabi Indian origin	A focus group study was conducted between 2001 and 2003, involving 49 British South Asian individuals speaking English, Hindi, and Punjabi, aged 17–61 years. Data was collected on views of aging and aging-associated difficulties in initial groups. Following primary data collection, vignettes were used for more specific exploration of awareness and understanding of dementia in a second set of groups. Thematic analysis method was adopted to analyze data	<ul style="list-style-type: none"> <li>• The language used in the current literature and the media and in the community creates an incorrect portrayal of persons living with the symptoms of dementia and creates and supports further stigmas and misconceptions regarding experience living with dementia. This eventually abolishes the value of the expression of the lived experiences, adding to the disbelief and stigma</li> <li>• Perception of aging was as a time of withdrawal and isolation, and frequently mentioned health problems involved physical or emotional and cognitive impairment</li> <li>• Identified implications that symptoms of dementia partly resulted from lack of effort by the person themselves and possibly from lack of family care; thus overcoming own problems and family actions might be part of the solution</li> <li>• A sense of stigma and a lack of knowledge were identified about mental illness and services, along with disillusionment with doctors and exclusion from services</li> </ul>
Giebel et al. (2015)	Examining the barriers and facilitators in accessing to culturally appropriate mental health care among South Asian older adults with memory impairment, dementia, and mental illness	A literature search was conducted in Web of Knowledge, PubMed, and Ovid databases to search for literatures from 1984 to 2012 regarding South Asian older adults or their family carers, their understandings	The following factors were identified by South Asians and health professionals that prevented help seeking and access to care: a lack of knowledge of dementia and mental illness and of local services, stigma, culturally

Author (date)	Study purpose	Study design	Summary of key findings
MacKenzie J (2006)	Summarize findings from a 3-year project to develop and deliver culturally appropriate support group materials for South Asian and Eastern European family carers of relatives with dementia living in the United Kingdom	of mental illness and dementia, and their pattern of service use. Assessment of abstracts for relevance and three researchers rated the quality of each included study. A narrative synthesis was used to extract and chart data  Stage 1 involved semi-structured interviews for 21 participants to explore carers' experiences of caregiving. Stage 2 involved developing and delivering of three 10-week support group programs, specified to reflect the needs of carers (identified in Stage 1) in a range of preferred community languages. Follow-up interview was conducted in stage 3 with each of the family carers 6 weeks after the completion of group program	preferred coping strategies, and linguistic and cultural barriers in communication and decision-making  Understandings of dementia in different cultural contexts can become operationalized through stigma processes, thus influencing the ways in which person with dementia and their family carers' participation in formal and informal support programs
Lee et al. (2005)	Identify and compare the interpersonal experiences of stigma in patients with mental health impairments, schizophrenia, and diabetes mellitus in Hong Kong	Four focus groups were conducted to develop a self-report questionnaire. Data were collected from outpatients	Stigma was more frequently experienced among people living with mental health impairment from family members, partners, friends, and colleagues than those living with diabetes
Liu et al. (2008)	Examining the relationship of stigma and dementia among Chinese and Vietnamese family caregivers	32 qualitative interviews were conducted among Chinese and Vietnamese family caregivers living in the USA to collect narrative data and identify key themes	Two sources of stigma were identified: the stigma of chronic and severe mental illness and a stigma reflecting negative stereotypes of aging or the elderlies. Chinese and Vietnamese cultural perceptions of normal aging accommodate different paths of aging, some more and some less desired. With regard to persons with dementia, a "normalized" but negative path of aging carried with it significant stigma that was distinct from but in addition to the stigma of chronic and severe mental illness
Yang and Kleinman (2008)	An analysis of how "face" is embodied in China to understand an articulation of how the social aspects of	Analysis of existing conceptual writings and empirical studies	Face—both moral and in particular social face—can be seen to function as forms of symbolic capital. Shame

Author (date)	Study purpose	Study design	Summary of key findings
	stigma might incorporate the moral standing defined within a local context		and “loss of face” were identified to lead to stigmatization associated with mental health impairments including dementia
Kong et al. (2009)	To identify and describe experiences of Korean immigrant caregivers regarding American nursing home placement of their non-English-speaking older relatives with dementia	Qualitative descriptive methods and qualitative content analysis using a total of 17 semi-structured interviews with 10 Korean immigrant family caregivers	The “Korean way of thinking” was identified to be a fundamental cultural belief about caregiving. Six major themes were identified: (a) I never thought about a nursing home; (b) if I think in a Korean way, I feel; (c) nursing home staff cannot communicate with; (d) my care recipient maintains Korean culture; (e) nursing home services are better than expected but; and (f) my care recipient is more vulnerable because of dementia
Iliffe and Manthorpe (2010)	Argue that sociocultural/ethnic issues are applicable to all individuals with dementia, independent of apparent ethnicity, and that promotion of cultural competence in service provision should not be relegated to an ethnic minority agenda	Analysis of existing literature	The experience of accessing to support is associated with three key factors: <ol style="list-style-type: none"> <li>1. Language and literacy</li> <li>2. Religious belief and cultural practices</li> <li>3. Coping mechanism and social support</li> <li>4. Protective factors</li> </ol>
Bunn et al. (2012)	Evaluate the qualitative evidence regarding how individuals accommodate and adapt to the diagnosis of dementia and its immediate consequences, to guide practice	Systemic review of qualitative studies using 102 studies from PubMed, PsycINFO, Embase, CINAHL, and the British Nursing Index databases. Thematic analysis was conducted	Three overarching themes emerged from the study: (1) pathways through diagnosis, including its impact on identity, roles, and relationships; (2) resolving conflicts to accommodate a diagnosis, including the acceptability of support, focusing on the present or the future, and the use or avoidance of knowledge; and (3) strategies and support to minimize the impact of dementia
Mukadam et al. (2011)	Explore the factors due to which people from minority ethnic (ME) groups with dementia present later to specialist, diagnostic, and	Systemic review using three quantitative and ten qualitative studies	Barriers to accessing support for dementia included not conceptualizing dementia as an illness; believing dementia was a normal

Author (date)	Study purpose	Study design	Summary of key findings
	therapeutic dementia services		consequence of aging; thinking dementia had spiritual, psychological, physical health or social causes; feeling that caring for the person with dementia was a personal or family responsibility; experiences of shame and stigma within the community; believing there was nothing that could be done to help; and negative experiences of health-care services. Accessing to help was facilitated by recognition of dementia as an illness and knowledge about dementia. Minority of the ethnic groups face significant barriers to help seeking for dementia, often diagnosed in late stage
McMurtagh et al. (2009)	To explore whether regression to a primary language may be associated with development of cognitive impairment and increased risk for development of dementia	Studying two cases of bilingual patients who presented with early symptoms of dementia after regression to their primary language	The cases described in the report support the hypothesis that an association may exist between regression to the use of primary language among bilinguals and poor cognitive performance and diagnosis of dementia
Rosendahl et al. (2016)	Explore and elaborate the experiences of family members and professional caregivers regarding the care provided to immigrants with dementia in group homes in Sweden	Exploratory, descriptive study with a qualitative approach was chosen using in-depth semi-structured interviews. Qualitative content analysis was conducted to analyze data	Three main categories were determined with seven subcategories. The first main category was a new living situation which included the following subcategories: adjusting to new living arrangements and expectations regarding activities and traditional food at the group home; the second main category, challenges in communication with the subcategories: limited communication between the immigrant with dementia and the Swedish-speaking nursing staff and the consequences of linguistic misunderstandings and varied communication in a common language; and the third main category, the role of the family member at the

Author (date)	Study purpose	Study design	Summary of key findings
Mendez et al. (1999)	Explore the linguistic state of bilingual individuals with dementia	Survey 51 patients who reported regular use of another language, as well as varying fluency in English, and who presented for an evaluation because of progressive memory or cognitive problems such as dementia	group home with the subcategories: a link to the healthy life story of the family member with dementia and an expert and interpreter for the nursing staff Despite patients' differences in educational level, age at acquisition of English, frequency of use, and baseline fluency in English, a greater preference of the patients for their original language and decreased conversation in English was reported by all participating caregivers. With regard to characterizing the errors made by patients, majority of caregivers stated a tendency for words and phrases from the mother language used within English conversational speech
Kim et al. (2014)	Explore the relationship between nursing assistants' communication style and behavioral symptoms of individuals with dementia, focused on Korean American older adults with dementia residing in nursing homes	Reviewing currently available studies using eight studies from PubMed, CINAHL, PsycINFO, and ProQuest Digital Dissertations databases	Utilization of familiar language can increase an intervention's effect to potentially reduce or prevent behavioral symptoms of dementia for immigrants from various countries

## Author details


Winnie Sun<sup>1\*</sup>, Srijia Biswas<sup>1</sup>, Michelle Dacanay<sup>1</sup> and Ping Zou<sup>2</sup>

1 Faculty of Health Sciences, University of Ontario Institute of Technology, Oshawa, Canada

2 School of Nursing, Nipissing University, Toronto, Ontario, Canada

\*Address all correspondence to: [winnie.sun@uoit.ca](mailto:winnie.sun@uoit.ca)

## IntechOpen

© 2019 The Author(s). Licensee IntechOpen. This chapter is distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/3.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. 

## References

- [1] Government of Canada, "Dementia," Government of Canada [Online]. 2016. Available from: <https://www.canada.ca/en/public-health/services/diseases/dementia.html> [Accessed: 28-03-2017]
- [2] Alzheimer's Association. 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2015;11(3):332-384. Retrieved from: [https://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](https://www.alz.org/facts/downloads/facts_figures_2015.pdf)
- [3] Statistics Canada. Seniors. 2016. Retrieved from: <http://www.statcan.gc.ca/pub/11-402-x/2012000/chap/seniors-aines/seniors-aines-eng.htm>
- [4] Makwarimba E, Stewart M, Simich I, Makumbe K, Shizha E, Anderson S. Sudanese and Somali refugees in Canada: Social support needs and preferences. *International Migration*. 2013;51(5):106-119
- [5] Scheltens P, Blennow K, Bretler MMB, de Strooper B, Frisoni GB, Salloway S, et al. Alzheimer's disease. *Lancet*. 2016;338(10043):505-517. DOI: 10.1016/S0140-6736(15)01124-1
- [6] Wong SL, Gilmour H, Ramage-Morin PL. Health Reports: Alzheimer's Disease and other Dementias in Canada. Statistics Canada [Internet]. 2016. Available from: <https://www.statcan.gc.ca/pub/82-003-x/2016005/article/14613-eng.htm>. [Cited: 26-03-2018]
- [7] Alzheimer Society of Canada. Normal Aging vs Dementia. Alzheimer Society of Canada [Internet]. 2017. Available from: <http://alzheimer.ca/en/Home/About-dementia/What-is-dementia/Normal-aging-vs-dementia> [Cited: 26-03-2018]
- [8] Dubois B, Padovani A, Scheltens P, Rossi A, Dell'Agnello G. Timely diagnosis for Alzheimer's disease: A literature review on benefits and challenges. *Journal of Alzheimer's Disease*. 2016;41(3):617-631. DOI: 10.3233/JAD-150692
- [9] Dementia in the Asia Pacific Region. Alzheimer's Disease International. 2014. Available from: <https://www.alz.co.uk/dementia-in-the-asia-pacific>
- [10] Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*. 2009;11(2):217-228
- [11] Reinhard SC, Given B, Petlick NH, Bemis A. Supporting family caregivers in providing care. In: *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville: Agency for Healthcare Research and Quality; 2008
- [12] Alzheimer Society Canada, "Dementia Numbers in Canada," Alzheimer Society Canada [Online] 2017. Available from: <http://www.alzheimer.ca/en/About-dementia/what-is-dementia/Dementia-numbers> [Accessed: 11-03-2017]
- [13] Koehn S, Neysmith S, Kobayashi K, Khamisa H. Revealing the shape of knowledge using an intersectionality lens: Results of a scoping review on the health and health care of ethnocultural minority older adults. *The International Journal of Aging and Society*. 2013;33:437-464
- [14] Statistics Canada, "Population growth: Migratory increase overtakes natural increase," Statistics Canada [Online] 2017. Available from: <http://www.statcan.gc.ca/pub/11-630-x/11-630-x2014001-eng.htm> [Accessed: 25-03-2017]
- [15] Giebel CM, Zubair M, Jolley D, Bhui KS, Challis D. South Asian older adults with memory impairment: Improving assessment and access to dementia care.



- International Journal of Geriatric Psychiatry. 2014;**30**(4):345-356
- [16] Swaffer k. Dementia: Stigma, language, and dementia-friendly. SAGE. 2014;**13**(6):709-716
- [17] Fontaine JL, Ahuja J, Bradbury NM, Phillips S, Oyebode JR. Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*. 2007;**60**(6):605-614
- [18] Mackenzie J. Stigma and dementia. *Dementia*. 2006;**5**(2):233-247
- [19] Lee S, Lee MT, Chiu MY, Kleinman A. Experience of social stigma by people with schizophrenia in Hong Kong. *British Journal of Psychiatry*. 2005; **186**(2):153-157
- [20] Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*. 2008;**23**: 283-299
- [21] Yang LY, Klainman A. 'Face' and the embodiment of stigma in China: The cases of schizophrenia and AIDS. *Social Science & Medicine*. 2008;**67**(3):398-408
- [22] Kong E-H, Deatrck JA, Evans LK. The experiences of Korean immigrant caregivers of non-English-speaking older relatives with dementia in American nursing homes. *Qualitative Health Research*. 2010;**20**(3):319-329
- [23] Iliffe S, Manthorpe J. The debate on ethnicity and dementia: From category fallacy to person-centred care? *Aging and Mental Health*. 2004;**8**(4):283-292
- [24] Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Medicine*. 2012;**9**(10)
- [25] Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*. 2011;**26**:12-20
- [26] McMurtay A, Saito E, Nakamoto B. Language preference and development of dementia among bilingual individuals. *Hawaii Journal of Medicine & Public Health*. 2009;**68**(9):223-226
- [27] Rosendahl SP, Soderman M, Mazaheri M. Immigrants with dementia in Swedish residential care: An exploratory study of the experiences of their family members and nursing staff. *BMC Geriatrics*. 2016;**16**:18
- [28] Mendz M, Perryman KM, Ponton MO, Jeffery CL. Bilingualism and dementia. *The Journal of Neuropsychiatry and Clinical Neurosciences*. 1999;**11**(3):411-412
- [29] Kim H, Wood DL, Phillips LR. Nursing assistants' communication styles in Korean American older adults with dementia. *Journal of Transcultural Nursing*. 2014;**26**(2):185-192
- [30] Wong SL, Gilmour H, Ramage-Morin PL. "Health Reports Alzheimer's Disease and other Dementias in Canada," Statistics Canada [Online] 2016. Available from: <http://www.statcan.gc.ca/pub/82-003-x/2016005/article/14613-eng.htm> [Accessed: 27-02-2017]
- [31] Statistics Canada, "Population Growth: Migratory Increase Overtakes Natural Increase," Statistics Canada [Online] 2017. Available from: <http://www.statcan.gc.ca/pub/11-630-x/11-630-x2014001-eng.htm> [Accessed: 11-03-2017]