



FORUM REPORT

CULTURALLY RESPONSIVE DEMENTIA CARE
FOR THE SOUTH ASIAN COMMUNITY

SEPTEMBER 29, 2018



SOCIAL PLANNING
COUNCIL
of Ottawa



Le CONSEIL de
PLANIFICATION SOCIALE
d'Ottawa

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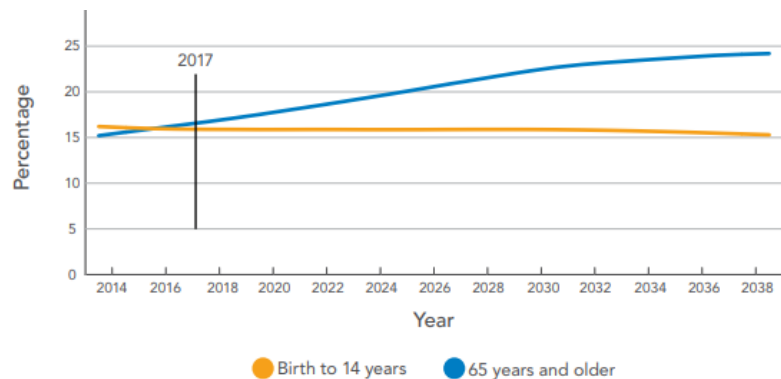
INTRODUCTION

BACKGROUND

The Alzheimer’s Society defines the word “dementia” as a general term for the loss of mental abilities severe enough to interfere with everyday life. Alzheimer’s is the most common type of dementia; however, there are other forms of the disease. Many people often refer to dementia as “senility”, which reflects the widespread but incorrect belief that significant mental decline is a normal part of aging. In truth, dementia is the result of physical changes in the structure of the brain. Dementia affects memory, communication and language skills, the ability to focus and pay attention, reasoning and judgment, and visual perception. Most forms of dementia are progressive. As a result, most patients experience a gradual worsening of symptoms and an increase in care needs.

As the Canadian population ages (Fig. 1), the number of people with dementia is expected to increase by as much as 66% by the year 2032 (Statistics 2017). As the number of people with dementia grows, the need for culturally responsive dementia care services will too. Culturally responsive¹ care refers to health care services that are respectful of, and relevant to, the health beliefs, practices, cultural, and linguistic needs of diverse populations and communities. It requires a working knowledge of culture and acknowledgement of the challenges faced by diverse communities (State of Victoria, Department of Health, 2009).

FIGURE 1: CURRENT AND PROJECTED DISTRIBUTION OF ONTARIO RESIDENTS AGED 14 YEARS AND YOUNGER AND 65 YEARS AND OLDER, 2013 TO 2038



Source: Statistics Canada (2014). Projected population by projection scenario, age and sex, at July 1, Canada, provinces and territories, annual (persons).

According to the 2016 Census, South Asians² represented 5.6% of the Canadian population, making them the largest visible minority in Canada. Although dementia care services are available for everyone in the city, cultural differences make a South Asian patient with dementia less likely to seek services and treatment for dementia compared to their majority counterpart (McCleary et al., 2012).

“Imagine a world where a diagnosis of dementia is not met with fear, but with hope and understanding...”

-Canadian Federal Minister of Health, Honourable Ginette Petitpas Taylor

South Asian patients with dementia and their family caregivers face unique challenges throughout the journey of care - from early diagnosis to end-of-life care. Lack of knowledge and stigma against mental health issues, a fear of discrimination by the community and health care providers, beliefs against seeking professional help, and an unavailability of culturally inclusive services are all barriers South Asian Canadians face when accessing dementia care services (Holmes, 2018). In response to these challenges, the Social Planning Council of Ottawa, Champlain Community Support Network, and Indo-Canadian Community Center Seniors Program hosted a forum to explore the development and implementation of an adult day program for dementia patients of South Asian descent.



¹ Cultural responsiveness describes the capacity to respond to the health care issues of diverse communities.

² The term “South Asians” refers to people who were either born in or can trace their ancestry to a South Asia country, Afghanistan, India, Pakistan, Sri Lanka, Bangladesh, Bhutan, Nepal, or Maldives.

ACKNOWLEDGEMENTS

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We are also thankful to our committee members for their assistance in making the forum a reality and their help in editing the Final Report.

- Dr. Indu Gambhir, Past Chair, Seniors Program, Indo-Canadian Community Center
- Mr. Anil Sukhija, Chair, Seniors Program Indo Canadian Community Center
- Dr. Prabir Neogi, Deshantari of Ottawa, Carleton
- Dr. Albert Banerjee, Co-investigator with Imagining Age-Friendly Communities within Communities: An International Study of Promising Practices. Research Associate with the Trent Centre for Ageing and Society.
- Kieran Holmes
- Kirti Kaila, BSO, IIWCC, BScN, GPA coach
- Sybil Braganza, Coordinator, Ethnocultural Seniors Project, Social Planning Council of Ottawa

FORUM PROGRAM

Culturally Responsive Dementia Care

Date: Saturday, September 29, 2018

Time: 10:00am – 2:00pm

Location: East India Company, 1995 Robertson Road, Ottawa, Ontario

- **Registration and Refreshments**

- **Greetings and Welcoming Remarks**

Anil Sukhija, Chair, Seniors Program Indo-Canadian Community Center

- **Key Note Address**

Kirti Kaila, BSO, IIWCC, BScN, GPA coach

- **Research Paper by Kieran Holmes**

Presented by Anita Barewal

- **Break**

- **Panel Presentations**

Dr. Indu Gambhir, Uttara Bhargava, Kailey Lewis, and Zeba Taj

- **Focus Group Discussion**

- **Lunch and Reporting Back**

- **Closing Remarks**

Dianne Urquhart, Social Planning Council of Ottawa

FORUM SUMMARY

The forum was attended by health care professionals, service providers from various organizations, and members of the South Asian community.

The objectives of the forum were:

- To gain a better understanding of the challenges South Asians face in accessing dementia care services;
- To address the needs of South Asian families and caregivers that are caring for a loved one with dementia;
- To identify current programs and best practices that can be used by service providers to make their programs more culturally responsive; and most importantly,
- To determine if a dementia care adult day program for South Asians is needed and what it would look like.

In the key note presentation delivered by Kirti Kaila, a Behavioural Supports Ontario nurse, outlined the health care barriers encountered by South Asian dementia patients and their families. The barriers discussed had a common theme—culture. The presentation highlighted the value of culture in the South Asian community and pointed to the need for South Asians to advocate for their cultural needs. More specifically, the presentation emphasized that behavioural management for dementia patients can only be properly executed when there is a complete understanding of an individual’s lifestyle. Health care providers must accommodate a patient’s cultural needs and use a person-centered care model to ensure the best patient outcomes.

Key messages from the keynote address were:

- Existing dementia care services are not working well for the immigrant population in Ottawa,
- Service providers should modify existing programs to incorporate different languages and culturally appropriate food and activities to ensure participation by South Asians;
- The lack of knowledge of dementia and dementia related health care services in the South Asian community tends to normalize the disorder, which delays diagnosis;
- Stigma against mental health issues in the South Asian community needs to be addressed and reduced by promoting awareness of the topic;
- A dementia care adult day program for South Asians would benefit both patients with dementia and their caregivers if it includes culturally appropriate services and activities.

Anita Barewal presented a summary research written by Kieran Holmes on the topic of culturally responsive dementia care for South Asians. The presentation provided an overview of a South Asian family’s perspective on barriers that exist with respect to accessing dementia care in the community, and the

perspectives of caregivers and health care providers regarding obstacles faced in providing culturally responsive dementia care.

Key messages from the presentation were:

- Lack of knowledge about dementia, beliefs on dementia-related symptoms and care seeking, and stigma against mental health issues put the South Asian community at a great disadvantage when it comes to recognizing signs of dementia and accessing dementia care services.
- Language and cultural sensitivities, disparities in pharmacological treatment and cognitive assessment, methods to promote help seeking, experiences and beliefs of service providers, and recognizing heterogeneity in the South Asian population make providing culturally responsive care a challenge for caregivers' and health care providers.

The panel presentation summarized in Appendices D-G was used to provide the participants of the forum with information about dementia, dementia care day programs, and personal stories that highlight the experiences of caring for someone with dementia.

Key messages from the panel presentation:

- Health care provider's lack of knowledge about types of dementia, cultural norms of South Asians, and language barriers can make it difficult to make a prompt dementia diagnosis;
- An early diagnosis of dementia is extremely important because medications for symptom management only work at early stages, and early diagnosis allows for timely connectivity with dementia resources which reduce patient isolation and caregiver stress
- Current dementia care services are not culturally responsive and the South Asian community's stigma against mental health issues cause an increased burden of care for family caregivers resulting in caregiver stress and isolation
- Adult day programs, like the Algonquin Adult Day Program, have many benefits including: socialization, physical activity, stimulation, delayed institutionalization for dementia patients, and respite for caregivers.



FOCUS GROUP DISCUSSION

Forum participants were divided into six groups of eight people. Led by a facilitator, the groups discussed four important questions about dementia related educational and care needs of South Asians Ottawans.

QUESTIONS 1 & 2: ASSESSING COMMUNITY KNOWLEDGE



The focus groups were asked the following questions in order to assess their knowledge about dementia and dementia care services available in the city of Ottawa:

Question 1: *What does dementia mean to you? What is the difference between normal aging and dementia?*

In answering the first question, the participants exhibited vague knowledge about dementia. Groups described dementia solely as a “memory loss illness”.

Moreover, they found it difficult to

differentiate between normal aging, dementia, and depression. Focus group participants discussed the need for more awareness and education on the topic and admitted their lack of understanding about the complexity of dementia. These results are consistent with previously conducted research that also showed that the South Asian community lacks knowledge about dementia (La Fontaine et al., 2007).

Stigma about mental health and dementia was a major part of the discussion. Focus group participants expressed that stigma is a major problem in the community and one of the leading reasons why people do not seek help when they start noticing signs of dementia. This stigma also stems partially from a lack of knowledge.

The Problem:

Inadequate knowledge of dementia and stigma against the illness are both issues known to impede an early diagnosis and compromise patient care (Bradford et al., 2010). For instance, memory loss can go unnoticed or be perceived as a normal part of aging until the occurrence of a catastrophic or “key event” like wandering outside at night or forgetting the name of a close family member. This can be stressful and terrifying for both the dementia patient and their family. In such cases, the patient has already begun rapidly deteriorating and

symptom management may no longer be effective. To prevent such situations, these issues must be addressed.

Question 2: *a. What services are available for people with dementia? Or for those who care for them?*

b. Of these services which ones work well, and which ones do not?

Participants exhibited limited or vague knowledge about the available services and displayed almost no knowledge on how to access the services. Most groups named services like LTC facilities, Champlain Local Health Integration Networks, the Alzheimer's Society, and dementia care day programs. However, there was no real consensus on what these services did and whether they were effective or not. The groups discussed the fact that not all services were culturally inclusive, which they understood hinders access to these care services. Some participants were completely uninformed about dementia care services in the city and expressed the need for education on available services. All participants emphasized the difficulty of accessing and navigating dementia care services.

The Problem:

Family caregivers and patients in dire need of services are not able to access them simply because they do not know what is available to them. Even when there is an awareness of services, people may not be able to connect to them due to difficulty in navigating the health care system. Most services require referrals from different branches of health care, which can be quite confusing. When people are eventually connected with available services, they may not be able to use them to their full potential due to cultural barriers. For example, a personal support worker coming to look after a senior South Asian patient with dementia may not be able to adequately communicate with them and would therefore require a family member or caregiver to stay home and act as an interpreter. Similarly, patient with dementia at a LTC facility where their dietary needs are not met may require family members to drop food off for them. This results in family caregiver burnout and the deterioration of the caregiver's health, along with the patient's health. Moreover, funding cuts to services mean that health care coordinators are faced with the difficult challenge of deciding who is eligible for services, thereby reducing the availability of services to people who really need them. These issues all lead to compromised patient care and must be addressed in order to better serve the community.

The Solution:

- Health care providers and policy makers have the most challenging task: they must implement cultural competency in the current health care system, especially in dementia care services. To do so, health care providers must familiarize themselves with culturally relevant issues that prevent South Asians from seeking or receiving their services. Simplifying the process of accessing care services and making dementia care services available in a variety of South Asian languages, such as Hindi, Punjabi, Gujrati, Bengali, Tamil, and Urdu, will reduce the time it takes to get access to services. Adopting a person-centered approach to health care where the patients and their families are involved in care planning is integral to providing high quality health care and will promote early diagnosis of dementia. The South Asian community is highly diverse, and as such, no one approach will be suitable for all South Asian patients. Using the Newcastle model (James, 2011), nurses, physicians, social workers, and other

health care providers can deliver care that takes into consideration individual life history and experiences, social environment and culture, and personality, essentially viewing the patient more holistically (Fig 2.). Specifically, the Newcastle model can help health professionals better understand a dementia patient's care needs and why a patient may find a situation difficult or why they may behave in a particular way. The Newcastle model will also aid health professionals to better understand the needs of South Asians patients in existing care programs. Modifying existing care services to make them more culturally responsive will allow services to be used to their full potential.

- For best patient outcomes, educating health care providers on the cultural requirements of South Asians will be fundamental in changing the trajectory of dementia care services. The South Asian community, collectively, must highlight the health care needs of patients with dementia and educate one another about dementia and dementia care services. Raising awareness in the community using various methods, like educational presentations and social gatherings to discuss dementia related issues, will reduce stigma against dementia. Most importantly, awareness will help to clarify the distinction between normal aging and dementia, eliminating the normalization of dementia. In turn, this will encourage people to be more proactive in seeking care services.
- South Asian seniors who are experiencing early symptoms of dementia must discuss health concerns and care needs with family and health care providers. This is a necessary step to ensure a prompt diagnosis is made and care needs are accommodated. An early diagnosis means dementia patients have more control over their life, even in later stages of the disorder. With the help of a health care provider and their family, the senior will be able to be involved in creating a health care plan that they themselves are satisfied with.
- Family members of South Asian seniors can help their loved one by advocating for their health care needs, listening to them, and ensuring they are socially and mentally engaged. Family members should also be aware of dementia symptoms and look out for relevant signs of cognitive decline. Such steps will prevent isolation late diagnosis and ensure that care needs are met.

QUESTION 3: DEMENTIA CARE NEEDS

The focus group was asked the following question to identify services that would address the challenges South Asians face with respect to dementia care:

Question 3: *What services would people caring for a dementia patient like to see?*

Educational Services

The focus group heavily advocated for more education about dementia and dementia services. More education on the topic would decrease stigma and promote help seeking. In particular, the following needs were identified:

- Services where families can get more information on how to get care for a loved one suffering from dementia

-
- An easy to follow map of disease progression in different South Asian languages (Hindi, Punjabi, Gujrati, Bengali, Tamil, and Urdu) to make the stages of dementia easier to understand
 - Funding for existing South Asian groups in the city to hold dementia seminars for seniors to better understand the condition
 - Support groups or counselling services specifically for South Asians to promote discussion about dementia and decrease stigma
 - Radio or TV programs discussing dementia related topics available in different regional languages
 - Training programs for health care providers on the importance of culturally responsive care and best practices to care for South Asian patients

Care Services

The need for culturally appropriate care services was a recurring theme throughout the focus group. The following are examples of programs identified that exemplify this theme:

- LTC facilities with diverse staff who can speak South Asian languages, and culturally appropriate food and activities
- Government-funded or subsidized South Asian-specific dementia care day programs to promote social inclusion and respite for family caregivers
- Services like Meals on Wheels to provide South Asian food
- Volunteers, who are trained to provide culturally responsive care, and to run home drop-in program to promote socialization and reduce isolation

QUESTION 4: ADULT DAY PROGRAM

The focus group was asked the following questions in order to elicit suggestions about how an adult day program for South Asians with dementia would be successful:

Question 4: *If there was an Adult Day Program where your loved one with dementia could go for the day to give you some rest:*

- *What services or activities would you like them to have access to during the day?*
- *Would getting a break help you, the caregiver, in your home and ensure your loved one could stay at home longer?*
- *If there was a cost to these services, how much would you be willing to pay?*

The participants of the focus group suggested that the following activities should be included in an Adult Day Program:

- Physical activities like yoga, dancing, and group walks
- Outings to cultural destinations, such as libraries, museums, and parks
- Meditation
- Health presentations
- Do-it-yourself arts and crafts

-
- Providing South Asian food, especially vegetarian food
 - Conversations with youth volunteers
 - Storytelling
 - Transportation to and from activities
 - Entertainment events like movie showings or theatrical performances
 - Games like chess, carrom, snakes and ladders, and pachisi for mental stimulation
 - Ensure program facilitators have knowledge of the culture and the ability to speak a variety of South Asian languages

An adult day program with these services is likely to be successful as it will be culturally responsive and accessible to those who do not speak English. All participants in the focus group agreed that such a program would provide them respite and help avoid burnout, allowing them to take care of their loved ones at home for longer. Participants were willing to pay \$10-25 per day for this program.

NEXT STEPS AND CONCLUSION

The research paper by Keiran Holmes and this SPCO forum was the first phase in developing and implementing a dementia care adult day Program. This report includes many suggestions for as health care service providers and the South Asian community. These suggestions will help ease the challenges faced by South Asian Canadians in accessing health care services for dementia patients.

Going forward, the necessary steps needed to implement a culturally responsive dementia care model in Ottawa are:

- Community Partnership with Indo-Canadian Community Centre (ICCC) to educate and implement cultural awareness among health care providers and dementia awareness among the South Asian population in Ottawa
- Ease the difficulty of navigating the health care system by providing a roadmap to available services and how to access them in different South Asian languages (Hindi, Punjabi, Gujrati, Bengali, Tamil, Urdu)
- Develop and implement an adult day program for South Asians

Dementia care adult day programs exist in the Greater Toronto Area, as well as in the UK and Australia. These programs can be adapted to create a framework for a program that works for the City of Ottawa. For example, the South Asian Adult Day Program in Markham, Ontario offers culturally appropriate services in a variety of different South Asian languages and is completely funded by the Central LHIN. Similarly, the Community Home Assistance to Seniors Program in Richmond Hill, Ontario is an adult day program that provides support and supervision to South Asian seniors with age-related illnesses and it costs approximately \$5.25/per day. By gathering more information on how existing programs were implemented and executed, a successful and fully accessible day program can be created for South Asians with dementia in Ottawa.

RECOMMENDATIONS

ICCC Seniors will involve the South Asian community of Ottawa through their umbrella organization, the Indo-Canadian Community Centre (ICCC), in order to make this a truly community initiative.

1. Education and Awareness:

- Family members and seniors should be educated about the signs and symptoms of dementia;
- Workshops and presentations should be offered on a regular basis by Dementia Network Society, Alzheimer's Association and by health care professionals working in the field of Gerontology and Dementia;
- Through better education and knowledge building, seniors and their families should have the information they need to better deal with dementia.

2. Culturally Responsive Services and Information:

- Service providers and health care professionals should be open to working with families and take into consideration language and culture when making assessments and providing diagnoses.

3. Service Navigation and Information on Services Available in Ottawa:

- Seniors and their families should be made better equipped to navigate and access the health care they need.

4. Build a Framework for Adult Day Programs:

- Work with stakeholders, policy makers and funders to create more inclusive and culturally-responsive programs and services to support seniors and give caregivers respite;
- The model of care should consider aspects such as language, culture, social activities, food.

5. Pilot Adult Day Program and Follow-up

- Design and implement a pilot adult day program, using the South Asian community of Ottawa as the target audience;
- Logistical details, resource implications, timetable and other characteristics of the pilot project will be worked out during the design phase, to be followed by a submission for the allocation of funding;
- A project evaluation module should build into the follow-up phase;
- Depending upon the success of the pilot project, a full-scale project may be recommended.

CLOSING REMARKS BY DIANE URQUHART

Diane Urquhart spoke of the importance of providing dementia care that meets the needs to ethno-cultural seniors. She stressed that this can only be achieved when the community and service providers work in unison to develop a program that works for everybody. She indicated that the results of the Forum should be communicated to a broader audience, such as all three levels of the Canadian Government, funders, researchers, and educational institutions. In closing, she thanked the committee for all their effort in organizing the Forum.



APPENDIX A: FORUM EVALUATIONS

Overall forum evaluation	Excellent 14	Very good 10	Good 2	Fair 0	Poor 0
The topic of this forum is important to me.	Strongly agree 21	Agree 8	Disagree 0	Strongly disagree 0	Unsure 0
I like the format of the forum	Strongly agree 18	Agree 9	Disagree 1	Strongly disagree 0	Unsure 0
The keynote presentation was interesting and relevant	Strongly agree 16	Agree 13	Disagree 1	Strongly disagree 0	Unsure 0
The research presentation was interesting and relevant	Strongly agree 22	Agree 8	Disagree 0	Strongly disagree 0	Unsure 0
The panel presentation was interesting and relevant	Strongly agree 15	Agree 12	Disagree 0	Strongly disagree 0	Unsure 0
Participant category	Service Providers 7	Community members 20			

APPENDIX B: KEYNOTE SPEECH BY KIRTI KAILA

South Asian Seniors in Ottawa

In 2016, 4% of the Ottawa population was of South Asian descent. As the baby boomer cohort ages, the percentage of individuals 65+ years of age is expected to double by the year 2031. This also means an increase in South Asian seniors in the city. Such a dramatic increase in the city's senior population implies the requirement for the availability of more care services, especially ones that are culturally responsive.

Prevalence of Dementia in the South Asian population

Although South Asians are the largest visible minority in Canada, they are underrepresented in health studies and are less likely to receive help for conditions such as dementia when compared to the general population. Most health studies pertaining to the South Asian senior population have been conducted in the UK or Australia. To gain a better understanding about the prevalence and presentation of dementia in South Asian Canadians, more research is required. With South Asian specific dementia research, we will be better equipped to address the need for more culturally responsive care.

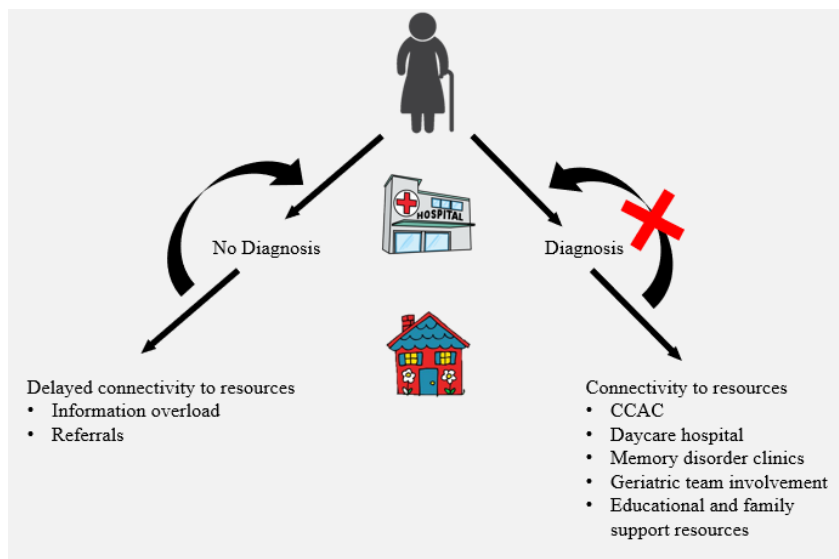
Importance of Culturally Responsive Care

The impact of culture on health care is significant. Culture influences how illnesses are perceived and experienced. Dementia care, specifically, requires a focus on behavioural management and care needs. Culture is an aspect of social environment and social environment influences behaviour. Addressing personhood, or a person's thoughts and experiences, is essential to providing holistic and patient-centered care and knowing about a person's cultural provides a platform.

How an early diagnosis provides best patient outcome?

Dementia can be a challenging diagnosis for everyone involved, including the patients, their families, and the care providers. Presentation of the condition and access to care depends on the cultural, social and educational background of the individual, as it can create unique challenges, potentially leading to a

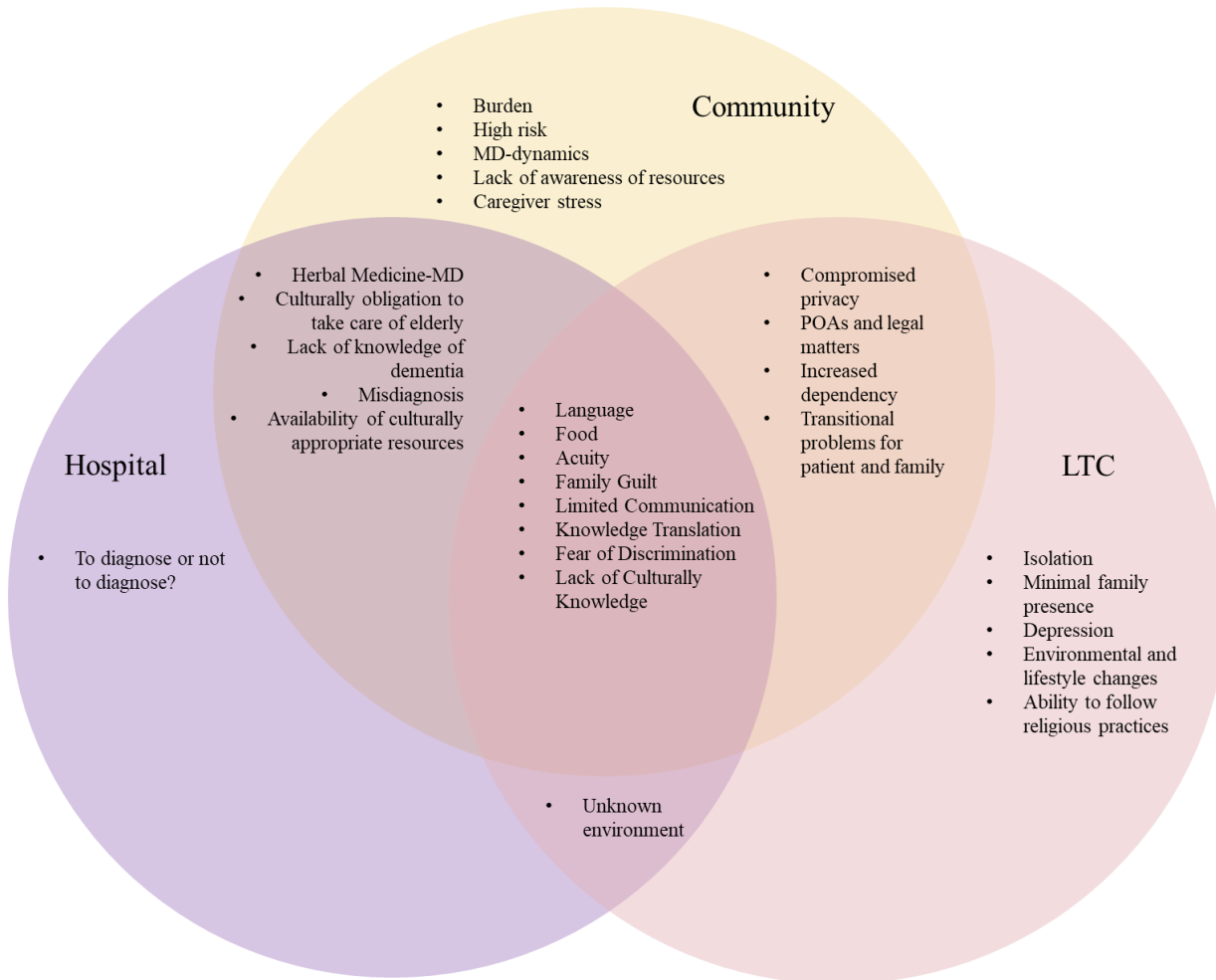
late diagnosis. With no diagnosis, a patient will make return trips to the hospital for dementia-related symptoms. This delays their connectivity to resources, creates information overload, and results in numerous referrals which compromises patient care and can be very exhausting for family caregivers and



the patient. With an early diagnosis, patients and families are connected to a variety of dementia related resources easing the transition from hospital to home, and reducing return trips to the hospital.

Challenges South Asians Face: Hospital, Community, Long-term Care Facilities

South Asian patients face a variety of challenges when accessing care in hospitals, in their community and in long-term care facilities. These challenges can collectively lead to a late diagnosis of dementia. Not only does this increase the burden on the health care system but it also increases the burden on patients and their families.



What can lead to better health care for South Asian dementia patients?

There are a few very important things a family member of a dementia patient can do for better patient outcomes. They must educate themselves about dementia and the resources available to them. Doing so reduces the stigma related to dementia and makes resources more accessible. Family being involved, aiding in decision making, and advocating for their loved one helps ensure the patient’s care needs are met.

Health care providers can also improve aspects of the way they provide care for better patient outcomes. First and foremost, cultural awareness and an understanding of how a person of South Asian descent may perceive health issues is necessary for a proper, early diagnosis of dementia. Patient-centered care plans that involve the family are very important. Because of the vast diversity of South Asian people in Canada, using a personhood model of care is critical. Lastly, more research studies focusing on people of South Asian descent will allow for more knowledge on best practices with regards to care for this community.

Most importantly, the South Asian community can do a few things to make sure people with dementia are better cared for. Verbalizing issues and increasing awareness would reduce stigma against mental illnesses which is essential to allow people to openly seek medical help. Promoting advocacy and highlighting cultural needs to health care providers will allow for more culturally responsive services. Collective education on the dementia care resources available at a facility or at home increases accessibility.

APPENDIX C: PAPER BY KIERAN HOLMES

The Family Perspective: Knowledge and Belief Barriers to Accessing Dementia Care in the South Asian Community

- **Recognition of Dementia**

The significant lack of knowledge about mental health disorders, specifically dementia, puts the South Asian community at a disadvantage when it comes to recognizing signs of dementia. In fact, many South Asian cultures do not have an equivalent term for dementia. Often, symptoms of dementia are normalized and are thought to be associated with signs of aging. Increasing awareness about dementia will improve accessibility and give families the tools to recognize symptoms of the disease and seek appropriate help.

- **Beliefs on Causes of Dementia Related Symptoms**

A UK study with participants of Indian descent found that the community used social, emotional and physical factors to explain away the symptoms of dementia. Isolation, loneliness, lack of family support, diabetes, heart disease, and high blood pressure were thought to be the cause of the cognitive decline. The participants in the study also expressed the belief that individuals with cognitive decline related to dementia should help themselves rather than seek professional help and suggested that increasing social interactions would help to alleviate the symptoms. In general, this study demonstrates the need to educate the South Asian community that dementia, like heart disease and diabetes, is a biological disorder that requires professional intervention and external help.

- **Beliefs of Care Seeking**

It is a common cultural norm for families to care for an elder with memory problems and to rely on religion rather than to seek professional help. Many people of South Asian descent associate caring for elders with familial pride and respect for the elder. Although this type of support can be beneficial for the affected person, delaying professional intervention can be problematic.

- **Stigma**

Mental health issues and seeking professional help for mental disorders is highly stigmatized by South Asians. The stigma stems from religious ideologies that associate dementia with religious and spiritual punishment and a lack of knowledge about the condition. Having a family member with a mental health disorder can also reduce the family's social standing and affect the marriages of later generations. This stigma is highly problematic because it results in a delayed diagnosis. South Asian groups highly stigmatizing dementia only seek help when a "key incident" occurs, such as wandering at night, car accidents, or forgetting a close family member's name. Like other barriers, stigma can only be reduced by increasing awareness about the disorder.

The Carers' and Health Providers' Perspective: Obstacles for Caregivers and Health Providers to Provide Culturally Responsive Care

- **Language and Cultural Sensitivity**

To provide South Asians with culturally responsive care, caregivers and health providers must adopt a model of care that acknowledges language, culture, and dietary restrictions and preferences. Language barriers present a major problem in providing appropriate care because they can make it difficult to detect dementia. People also find it difficult to express complex emotions in a different language. Furthermore, in the later stages of dementia, immigrants often revert to their mother tongue, making care services an uncomfortable experience. Interpreters are not ideal as they are rarely medically trained and critical health information may be lost in translation. The best way to deal with language barriers is to increase the diversity of staff as much as possible. This will also decrease the fear of discrimination many South Asian immigrants may feel when accessing health care.

- **Disparities in Pharmacological Treatment**

There is currently no research about South Asian immigrants and drug protocols related to dementia. However, there are several studies that show minority immigrants start taking dementia medication later and less frequently than non-immigrants. The disparity may exist because of active discrimination, differences in environments, cultural biases in cognitive measurements, or differences in attitudes towards dementia. This is an important concern that must be addressed in a dementia care program for South Asians. The lack of research on pharmacological treatment of South Asians and the effectiveness of anti-dementia medications for ethnic minorities is also another issue that requires attention.

- **Cognitive Assessment**

In addition to family caregivers being able to recognize and acknowledge symptoms of dementia, health practitioners must have the necessary skills and tools to promptly diagnose a South Asian patient with dementia in order to provide comprehensive care. A diagnosis is made using cognitive assessment tools, the most common one being the Mini Mental State Examination (MMSE). MMSE examines cognitive function and takes about 10 minutes. However it has been criticized for many reasons including: cultural bias, only being accessible to examinees who are fully literate, affected by social status variables, and is not accessible to everyone due to copyright issues. The Rowland Universal Dementia Assessment Scale (RUDAS), developed in Australia, is a better assessment tool as it addresses some of the problems with

the MMSE. RUDAS is available in 30 languages, minimizes cultural and educational biases, and takes about the same time as the MMSE. If health care providers are educated about the risk of cultural bias in such tests, they may be able to perform enhanced assessment for earlier and higher quality diagnosis.

- **Methods to Promote Help Seeking**

Although there is extensive research showing that the primary method to promote seeking out help is to increase knowledge and awareness about dementia, the best way in which this should be done is still undecided. There are various ways to educate South Asian people about dementia including: books, discussion with friends, educational radio programs, leaflets, etc. It is important to consider the target audience and what form of media would be most accessible to them. For example, an online video may not be the most suitable form of communication for a senior. Educating patients is one piece of the puzzle, but it is also important to educate physicians as they may possess inadequate knowledge about dementia. Using methods, such as campaigning, training videos, staff training, and personal information by word of mouth may be helpful in improving the knowledge of physicians. Physicians must also educate the public and ask questions to their South Asian patients and their families, specifically if they have been noticing any cognitive and behavioural changes, as South Asian families may not think these changes are relevant.

- **Experience and Beliefs of Service Providers**

The enormous demand for South Asian-specific dementia care services has service providers overwhelmed. There is a collective demand from service providers for more training about dementia care as they feel ill-equipped to deal with dementia patients and properly educate family members about the condition. Physicians believe the best way to explain to the South Asian community about dementia is to focus on dementia as a physiological illness, reducing stigma against the condition. It is also important to maintain an individualized care model which addresses the wide diversity of the South Asian population. Many service providers believe that instead of creating new dementia care services for South Asians, making existing services more culturally inclusive would be the best option.

- **Recognizing Heterogeneity in the South Asian Population**

The South Asian population varies linguistically, culturally, religiously, regionally, financially, and educationally. Therefore, a person-centered approach is essential to provide the most appropriate dementia care, even though this approach may be challenging. Perhaps this begins with dementia research studies addressing this heterogeneity, as currently there are very few that do so.

Services that Exist:

The search for South Asian-targeted services or day programs yielded extremely limited results. This could be due to lack of available programs, lack of effective advertising, or lack of funding. Any programs that were found fit in one of two categories: care services or education and outreach services. The GTA and the UK had the most programs, possibly due to a greater South Asian population in those regions.

Questions to Consider:

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- How would you rate your knowledge of dementia? Do you believe you could recognize the symptoms and attribute them to dementia?
 - If a family member was showing symptoms of or was diagnosed with dementia, would you be comfortable seeking professional help or support services? If not, who would most likely be the primary caregiver?
 - Do you believe there is a stigma surrounding mental illness and dementia in your community? Would this influence you in accessing external care?
 - Do you believe current dementia care services fit your cultural / linguistic needs as a South Asian? If not, how could these services be improved?
 - Have you ever felt discriminated against by a health provider due to your cultural background? If so, did this affect your decision in accessing care again?
 - What medium of spreading dementia awareness and education do you believe would be the most effective for you? Ex: Informal conversation with friends, radio programs, DVDs, TV advertisements, leaflets, videos on GP waiting room TVs, oral presentations by authorities in the field, websites or online videos, etc.
 - Do you feel that your regional background has cultural specificities that would need to be addressed compared to the generalized South Asian population? If so, please explain.
 - What type of culturally responsive care service appeals to you? Ex: Adult day cares, 24-hour nursing homes, at home services, support groups, education and outreach programs, etc.

APPENDIX D: PANEL PRESENTATION BY ANITA BAREWAL

Anita presented a summary of the paper written by Kieran Holmes. First, she discussed a South Asian family perspective about barriers that exist with respect to accessing dementia care in the community. She provided an overview on the issues related to:

- Recognition of dementia;
- Beliefs on the cause of dementia related symptoms;
- Beliefs on care seeking;
- And stigma against mental health problems.

In the second part of the presentation, Anita presented a carers' and health provider's perspective on obstacles that faced in providing culturally responsive dementia care. She discusses obstacles including:

- Language and cultural sensitivities
- Disparities in pharmacological treatment
- Cognitive assessment
- Methods to promote help seeking
- Experiences and beliefs of service providers
- Recognizing heterogeneity in the South Asian population

To conclude her presentation, she provided the group with some additional information about existing dementia care services for South Asians and questions that South Asian families and health care providers should consider about dementia and culturally responsive care.

APPENDIX E: PANEL PRESENTATION BY DR. GAMBHIR

When individuals approach old age, changes in the brain can occur resulting in symptoms which present as dementia. Dementia itself is not a specific disease but is the manifestation of significant impairments in at least 2 of the following core mental functions: memory, communication and language, ability to focus and pay attention, reasoning and judgement, and visual perception.

Dementia mainly presents as Alzheimer's, Parkinson's because of the presence of Lewy bodies, or vascular dementia. Infection, space occupying lesions, toxicity, head injury, metabolic conditions, nutritional deficits, and depression may cause dementia-like symptoms. However, these conditions do not truly cause dementia because the cognitive changes can be reversed. Dementia research and education is mainly focused on Alzheimer's, but it is important to realize that it is not the sole type of dementia. Due to lack of awareness, non-Alzheimer's dementia is often misdiagnosed or not diagnosed at all until it is too late.

Diagnosis of dementia involves clinical assessment and blood and brain imaging tests. Delayed diagnosis is commonly seen with South Asian patients due to several factors. Service providers may not be able to detect early stages of dementia because of a language barrier and lack of awareness of cultural norms. South Asian

population's and service providers' lack of knowledge of dementia may attribute the cognitive changes and early signs of dementia to normal aging or depression. Someone who is experiencing early signs of dementia may withhold information due to a fear of the consequences, stigma, and fear of isolation or abandonment.

There is limited treatment for dementia depending on the stage of the disease. There is no cure, but treatments involve medication for symptom management and support. By reducing isolation and keeping the diagnosed person in a familiar environment, the progression of the disease can be slowed down.

APPENDIX F: PANEL PRESENTATION BY KAILEY LEWIS

Kailey Lewis works for the Western Ottawa Community Resource Centre and the Algonquin Adult Program. Her presentation focused on what Adult Day Programs (ADP) are, how the program she coordinates works, and programs available in Ottawa. ADPs are for community members with a dementia diagnosis that allow them to engage in physical, social, and brain stimulating activities, giving their family caregivers respite.

ADPs have many benefits including:

- Socialization
- Physical activity
- Stimulation
- Respite time for caregivers
- Delayed institutionalization

At present, there are 15 adult day programs in the city, all with long waitlists. The Algonquin ADP sees 11 or more clients per day, costing \$23.50 per day.

APPENDIX G: PANEL PRESENTATION BY ZEBTA TAJ

Zeba Taj is a Seniors' Coordinator for the South Nepean Muslim Community (SNMC) and the Nepean Rideau Osgoode Community Resource Center. In her presentation, she used case studies to highlight common challenges faced by seniors and caregivers in the South Asian Community. Some of the challenges included language barriers, inaccessibility to ethnic food, stigma against mental health, and increased burden of care for family caregivers. Specifically, the increased burden of care on family caregivers results in stress, isolation and illness for the caregiver themselves. In concluding her presentation, she suggested three ways to help family caregivers.

- Encouraging members from different ethnocultural groups to pursue careers in health care and become caregivers.
- Provide ethno-specific long-term care centers
- Obtain more resources from Champlain LHIN for families, encouraging patients to be looked after by family

APPENDIX H: PANEL PRESENTATION BY UTTARA BHARGAVA

In her panel presentation, Uttara Bhargava, spoke about her experience as a care giver for her mother-in-law, Amma, who was suffering from dementia in the 1980s. When Amma moved to Canada to live with her son and Uttara, she presented signs of dementia. However, the path to a proper Alzheimer's diagnosis was hindered by the fact that the family was not able to recognize those signs due to lack of knowledge. Moreover, Amma's previous depression diagnosis led medical professionals to believe her depression was just manifesting in a different way. This caused great distress to Uttara, her husband and Amma because none of them were able to understand the cause of her altered behaviour.

When she was officially diagnosed with Alzheimer's, the family was connected with resources like the Alzheimer's society, which gave them much needed moral support. Despite that, Amma's condition was already rapidly deteriorating to the point where she was unable to do any personal care. The social worker suggested it was best for Amma to be placed in a long-term care facility even though it was not the cultural norm.

The care facility she was placed at was 45 minutes away from the family and also did not meet her cultural and spiritual needs. This resulted in Amma becoming more isolated and withdrawn, which was hard for the family to see. Uttara mentioned that the language barrier, inaccessibility to proper vegetarian food, lack of social interactions, and inability to meet spiritual needs were the greatest problems Amma faced in the care facility. As a former caregiver, Uttara suggested that a day program for South Asian patients with a dementia diagnosis should include:

- Some form of physical activity
- Games for their social and intellectual stimulation
- Education about dementia for the family
- Opportunities to celebrate cultural festivals, like Diwali.

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