

Navjot's Story: Moving Forward with Dementia

Also available in Punjabi, Hindi, and Urdu | ਪੰਜਾਬੀ ਵਿੱਚ ਵੀ ਉਪਲਬਧ ਹੈ | ਹਿੰਦੀ ਮੈਂ ਭੀ ਉਪਲਬਧ ਹੈ |
اردو میں بھی دستیاب ہے

When my grandmother was diagnosed with dementia, my family and I found ourselves navigating something we didn't quite understand. I had some knowledge of dementia, but others in my family did not. And since my grandmother was diagnosed early, there were no alarming signs aside from memory lapses, which were often seen as a normal part of aging. Her diagnosis was prompted by her day-to-day confusion, which was exacerbated during her travels between India and Canada due to the time zone differences.

As a family, we adapted to this new reality, scheduling appointments, searching for relevant resources, and supporting each other through my grandmother's journey with dementia.

Dementia in the South Asian culture

Living with dementia in South Asian Communities presents distinct challenges. In South Asian communities, dementia is often perceived through a lens shaped by cultural norms, traditional beliefs, and social expectations.

Unfortunately, a significant stigma surrounds dementia in these communities, contributing to the reluctance to openly acknowledge or discuss the condition.

The prevailing misconception that cognitive decline is merely a normal part of aging, coupled with a fear of societal judgment, can lead to delayed diagnoses and limited access to support services. Furthermore, the stigma associated with mental health challenges and cognitive disorders may result in individuals and families grappling with dementia in isolation, without seeking the necessary medical attention or community assistance.

Research from the UK has highlighted the challenges in South Asian communities related to a lack of awareness and stigma surrounding dementia, which can make it harder for people to access the right support. The research indicates that there are different types of stigma attached to dementia in these communities, ranging from cultural beliefs about aging, such as memory loss being a normal part of aging, to the fear of societal judgment due to dementia being seen as a mental health issue. Understanding these various stigmas is crucial for developing effective strategies to tackle the issue. However, it's essential to recognize that there's a lack of similar research in Canada. More studies are needed here to grasp how these types of stigma affect South Asian communities dealing with dementia in the Canadian context. This will help tailor support and awareness efforts to better fit the needs of our communities.

Raising awareness and fostering open conversations about dementia within South Asian communities is crucial to dispelling myths, reducing stigma, and promoting a more compassionate understanding of the condition.

A Lack of Culturally-Relevant Resources

The wide array of dementia support programs available, though excellent, often failed to bridge the cultural gap, rendering them less effective for those unfamiliar and unacquainted with Western culture and English. Despite the abundance of valuable services and resources designed to support both care partners and individuals living with dementia, there exists a notable gap in accessibility for individuals from South Asian communities. Linguistic and cultural barriers often hinder the effectiveness of these resources for those who belong to these communities. Many support services may be unavailable in languages commonly spoken in South Asian households, leading to a significant communication breakdown. Additionally, the cultural nuances surrounding dementia within the South Asian context might not be fully addressed, making it challenging for individuals and their families to relate to or benefit from mainstream resources.

Throughout my Ph.D. journey, I gained valuable insights into the unique challenges faced by South Asian families as they navigate the complexities of dementia. Taking on the role of a research assistant for a project centred on dementia marked the start of a transformative exploration. As I immersed myself in information on dementia awareness and support services, I couldn't help but notice a stark disparity for individuals within the South Asian community, a reality notably reflected in the experiences of my own grandmother. Despite the availability of commendable resources, the linguistic and cultural relevance crucial for effective support appeared conspicuously absent.

This realization fueled my determination to delve deeper, exposing a substantial gap in available services and research focusing on the experiences of South Asian Canadians navigating dementia.

This revelation propelled me to use my Ph.D. dissertation as a platform for advocacy, emphasizing the critical need for culturally sensitive and linguistically accessible dementia support within the South Asian community.



As my grandmother's diagnosis unfolded, the cultural challenges and the absence of culturally relevant resources became increasingly apparent, particularly when attempting to convey complex medical information in Punjabi. The confusion stemmed from terms that didn't readily translate, highlighting the broader issue of the underrepresentation of South Asian Canadians in dementia research. This underscored the necessity for research and information that captures the cultural nuances and challenges faced by South Asian communities.

The awareness of cultural disparity within Canada became more pronounced at a point when excellent dementia care programs, while effective, did not resonate with individuals unfamiliar with Western culture or English. My grandmother struggled to connect with activities like bingo or Hollywood movie nights, prompting questions about the lack of culturally appropriate dementia care within South Asian communities. This realization emerged, emphasizing the urgent need for cultural inclusivity in dementia discourse. The lack of awareness, fueled by misconceptions and limited resources, contributed to the silence surrounding dementia in these communities.

Navigating the dementia journey with my family, one lesson I've learned is the importance of understanding and addressing the cultural nuances of dementia care.

Doing so helps to fill information gaps, address cultural stigma, and support caregivers and people living with dementia as they navigate a dementia diagnosis. Each family's journey is unique and shaped by cultural backgrounds, and tailoring support accordingly is essential.

I hope more people in South Asian communities become aware of the realities of dementia. It's crucial to dispel misconceptions, encourage open conversations, and emphasize the need for culturally sensitive resources and support. Through my research, I aspire to contribute to this awareness, fostering understanding and driving positive change within South Asian communities' approach to dementia care.

To find resources about dementia for the South Asian community, visit:

www.forwardwithdementia.ca.