The Lived Experiences of South Asian Adult-Child Caregivers to Parents with Dementia Living in Western Nations

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Abstract

This capstone has found that while there are some positive elements to providing care to a parent with dementia within South Asian communities in Western countries, it is also a role that comes with many challenges. The caregivers face various systemic barriers related to medical systems, culture, religion, and language when trying to access external support. A cultural expectation of filial duty to care for one's parent in old age without help can also act as a barrier to seeking support. These barriers leave adult children in a position of taking on most of the care on their own. Minimal awareness of dementia within South Asian communities leaves caregivers struggling to learn about it while trying to adopt a new way of life. Caregivers often do not open up because of the ignorance, stigma, and shame surrounding dementia and the social pressure to be self-sufficient. This can prevent them from opening up to family and friends about what they are going through. The hardships ultimately result in decreased mental wellbeing for South Asian adult-child caregivers which warrant the need for mental health support specific to these populations.

Keywords: Dementia, South Asian, adult children, parents, caregivers, Western nations, lived experiences, filial duty, systemic barriers, mental health, stigma, coping, burden

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Lastly, I acknowledge myself for being brave enough to become a student again after a long break when it felt intimidating, and for doing what it took to pursue the path that will allow me to have the career and life that I have imagined for myself for a long time.

Dedication

I dedicate this capstone to all the South Asian adult children who find themselves in the position of caring for parents with dementia at home. It is far from an easy role to take on, and I can only imagine how challenging the journey must be. My hope is that this capstone will bring greater attention to your lived experiences so that you may feel better supported as you navigate this endeavor.

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Chapter One: Introduction

In this first chapter, I will begin by sharing some information about dementia and Alzheimer's disease including definitions and statistics. Then I will discuss seminal research in the area of South Asian family caregiving to highlight the gap in the literature that I intend to fill. I will then present my research question along with the purpose statement. Next, I will describe the conceptual framework and methodology including the type of literature review I have done, and how I located, collected, reviewed, organized, and analyzed the literature. This will be followed by a discussion of how the research is applicable to the field of counselling and psychotherapy. After that, I will state my positionality, reflect upon my biases, and indicate how I had planned to mitigate them prior to embarking on the research journey. Lastly, I will briefly define any terms that are specific to the topic before delving into the remaining two chapters.

Overview of the Topic

At present, global cases of dementia are over 55 million (World Health Organization, 2023) and will likely continue to rise as the ageing population increases since dementia is commonly diagnosed in older age (National Institute on Aging, 2022). Almost a quarter of the global population will consist of individuals over the age of sixty by the year 2050 (World Health Organization, 2024). If we look at Canada specifically, of a total population of around 40 million (Statistics Canada, 2023), over 770,000 people are currently believed to have dementia (Alzheimer Society, n.d.). As individuals of South Asian descent make up about seven percent of the total number of individuals residing in Canada (Statistics Canada, 2022), it is safe to assume that high rates of dementia are also found in older individuals of South Asian descent. This is not just the case in Canada but in other Western nations including the United Kingdom, which has almost an equal percentage of South Asian individuals residing within it

(GOV.UK, 2024). Dementia is characterized as cognitive decline, resulting from changes in the brain and most often is a result of developing Alzheimer’s disease although there are other causes (Alzheimer’s Association, n.d.b). It can manifest as behavioural changes, a decline in the ability to think, and changes in the way one relates to others**.** It may also make activities of daily living difficult to perform on one’s own (Alzheimer’s Association, n.d.a).

Within many South Asian communities, there is a cultural expectation that adult-children will live with or take in their parents and care for them at home rather than putting them in a care facility (Dhar, 2012). Given the prevalence of dementia worldwide as well as the aging South Asian population, one can infer that there are likely many adult children of South Asian descent providing care at home to their ageing parents with dementia. However, there is a lack of research with a particular focus on the lived experiences of this specific caregiver population, and the intention is that this capstone will start to fill this gap by bringing further insight in this area.

Earlier research has explored caregiving experiences within South Asian families in general and has uncovered valuable information. For example, Gupta and Pillai (2000) conducted a study with adult-child caregivers of Pakistani and Indian ethnic origins living in the United States who were caring for elderly parents or parents-in-law. The results showed that the caregivers tended to perceive their roles as more burdensome when they had to balance being a caregiver with several other roles such as being a parent to young children and being an employee. However, regardless of how many roles caregivers were juggling, having a close relationship with the parent or parent-in-law they were caring for decreased the level of perceived burden (Gupta & Pillai, 2000). Although this study provided insight into what could be a protective factor for South Asian adult-child caregiver mental health, it was not focused exclusively on caring for a parent with dementia. It is possible that there may be overlap; however, there are likely very distinct caregiving experiences associated with caring for a parent with dementia compared to caring for a parent with other conditions.

Other seminal research has challenged the notion that South Asian individuals will always have supportive social networks of family members and friends who will step in to provide care to one another when needed (Katbamna et al., 2004). For example, Katbamna et al. (2004) conducted a study on the lived experiences of South Asian adults caring for family members with physical and/or mental impairments in the United Kingdom. The researchers found that although most caregivers turned to their immediate family members for assistance, family were not always willing or able to help, leading some caregivers to manage primarily on their own (Katbamna et al., 2004). The authors argued that the assumption that family members in South Asian communities will always be able to help each other out, has led to South Asian families being offered less formal support which can be detrimental to caregiver well-being (Katbamna et al., 2004). This is an important insight which is reinforced in later research that will be discussed in the literature review. However, this study, like the work of Gupta and Pillai (2000), had a much broader scope and focus on South Asian adult-child caregiving experiences than this capstone will explore.

Purpose Statement

There is a lack of research that focuses specifically on the experiences of being a South Asian caregiver to a parent with dementia while living in a Western nation, and that is what the current study aims to explore. Hence the research question is, “what are the lived experiences of South Asian adult children providing care to parents with dementia in Western nations?” Several studies will be analyzed to gain insight in this area. Due to the sparsity of research with a particular focus on South Asian adult children, most of these studies will also include non-adult-child caregiver participants such as spousal caregivers**.** Some studies will include a mix of South Asian and non-South Asian participants. For the purposes of finding answers to the research question, the studies will be scanned carefully to ensure that only the South Asian adult-child caregivers' experiences are captured. The insights uncovered in this capstone are intended to inform counsellors of the unique lived experiences of this population so that they may be able to better support them with their mental wellbeing.

Research Framework and Methodology

Worldview

An important part of a research framework is a worldview, and the one I felt was most aligned with this capstone project is the constructivist worldview (Creswell & Creswell, 2018). One of the primary aims of research utilizing a constructivist worldview is to seek to understand the experiences of individuals and the meanings that are made of those experiences, while keeping in mind factors such as cultural influences and history (Creswell & Creswell, 2018). As the researcher interprets experiences and makes meaning of them, they also recognize that their own lived experiences will influence their perceptions (Creswell & Creswell, 2018).

Literature Review Approach

I felt that undertaking a traditional narrative review would be in accordance with my intentions for this capstone project. Efron and Ravid (2019) describe the traditional narrative review as an approach wherein the author brings forward the most important problems, trends, and debates to critically analyze the current research on a given topic. According to Efron and Ravid (2019), literature reviews can focus on one or more areas, two of which I zoned in on. I critically analyzed study methods as well as the findings and resulting conclusions which is consistent with the methodological structure of organizing information in literature reviews (Efron & Ravid, 2019). I also employed a qualitative approach for my research project as it is most in line with the constructivist worldview. According to qualitative researchers, subjective interpretations that individuals attribute to their experiences lead to the creation of knowledge (Efron & Ravid, 2019). Therefore, I only analyzed qualitative studies as they tend to contain rich information from participants often in a narrative format, including excerpts from interviews (Efron & Ravid, 2019). In my view, qualitative studies provide a more in-depth and person-centred source of information compared to quantitative works.

Literature Search

Research articles were found using the following databases: Psych Info, Psych Articles, Psychology and Behavioural Sciences Collection, and Google Scholar. The following terms were used in a variety of combinations to locate the most relevant articles: “South-Asian,” “Asian,” “Bangladeshi,” Bengali”, “Gujarati,” “Indian,” “Sri Lankan,” “Pakistani,” “Punjabi,” “adult-child caregivers or carers or caretakers,” “family members,” “relatives,” “informal caregivers or carers or caretakers,” “dementia or Alzheimer’s,” “caregiver experiences or caregiver burden or caregiver stress or caregiver fatigue or caregiver burnout or caregiver strain,” “transition to adult-child caregiver or carer or caretaker,” “role change,” “transition,” “equity,” and “access.” The search was filtered to only include peer-reviewed articles and dates of publication were not limited to allow seminal sources to be located, in addition to more recent literature. However, the articles that have been examined for the purposes of the literature review have been published within the last ten years or so.

Data Analysis

The information from the collected sources was organized in several different ways. First, all sources were saved into a citation manager program. I read through each one, highlighted the relevant information and organized them into different categories such as primary sources and secondary sources. I further organized the sources by tagging them according to relevant terms that emerged within them such as “filial duty,” and “mental health impacts.” I then used the ANTICS (Article Notetaking Index Cards) method outlined by Efron & Ravid (2019) to analyze the articles I was going to use for my literature review. My ANTICS included the following categories: article reference, main terms or themes, study purpose/question, study design, data collection and analysis, number of participants, participants’ relationships to the person with dementia, findings, critiques, and relevancy to my capstone. Lastly, I created a synthesis matrix table as proposed by Ingram et al. (2006). I found this to be an effective way to identify common themes amongst various studies, and to compare and contrast different findings within each theme in one place.

Contribution to the Field

The goal of my capstone project is to critically analyze the existing literature on the experiences of South Asian adult-child caregivers of parents with dementia living in Western nations. I wish to present an overview of how the experience is currently understood in research with the intention of bringing focus to this area where little research has been conducted previously. This is so that others may benefit and learn from the information that is uncovered, including gaining insight into how the findings can be applied to counselling psychology practice. My hope is that the findings from this review will help counsellors to develop an understanding of what South Asian adult-child caregiver experiences can look like and the impact the role can have on their lives. Having a greater understanding would allow mental health professionals to provide clients belonging to this population with the appropriate support.

Reflectivity and Positionality Statement

I am a female in my early thirties of a middle-class socioeconomic status with South Asian, specifically North Indian, Punjabi ethnic origins and Sikh religious origins. My parents immigrated to British Columbia in their mid-late twenties where I was born and have lived my entire life, and my grandparents immigrated shortly after. I grew up in a multi-generational home where my two younger siblings and I were raised by my parents, paternal and maternal grandmothers, and paternal grandfather. I still live in the same home with those family members apart from my maternal grandmother who passed away when I was 16 years old. I am bicultural, in that I have taken on certain values from Canadian western culture, which tends to be more individualistic as well as certain values from Indian culture which tend to be more collectivist. Like many of the adult-child participants in the studies that will be discussed, I too feel a strong South Asian culture-related obligation and duty to give back to my elders by caring for them at home in their old age as a way to repay them for raising me in my childhood. I already do this to an extent by accompanying my grandparents to their medical appointments, translating for them, and keeping track of their medical appointments, medications, and other treatments.

I have witnessed the devastating effects of dementia in a few of my extended family members. It has been especially difficult for their family caretakers who have primarily been their female adult-children or female adult-children-in-law. The case that is most prominent in my life at this time is my mother's aunt, who was diagnosed with dementia a few years ago. She has been rotating living with her adult-children similar to how the participants in some of the reviewed studies reported caring for their parents. Her symptoms have progressed to the point of suicide threats, and physical aggression toward herself and family members including me when she does not get her way. This is in addition to the many other symptoms such as incontinence, a loss of time and place perception, being constantly awake during the night, wandering, and having difficulty recognizing her children's faces. Due to the cognitive and behavioural changes that have resulted from the condition, her children are unable to leave her alone in fear that she may hurt herself or get lost. This has required them to significantly alter their day-to-day lives to provide care and supervision which has led to caregiving fatigue and burnout. Seeing the toll that becoming a caregiver to one's parent with dementia has taken on the lives of my extended family has prompted me explore the South-Asian adult-child caregiver experience further and learn more about not only the hardships of the role but the potential positives, and to gain an overall view of the caregiver experience beyond my extended family.

I recognize that the negative impacts of dementia which I have observed and experienced have made me biased towards viewing the role of caregivers as burdensome and difficult. This has required me to make a conscious effort to find the potential positives, which as the research has demonstrated, do exist. Additionally, since I have mostly seen women take on caregiving roles for elders in my immediate family, extended family, and overall South-Asian culture, it has made me biased in terms of assuming that this must be the case for the majority of South Asian families which may not necessarily be true. In my experience, there is a greater expectation for women to adequately manage all parts of their lives along with their caregiving duties compared to males despite often having an equal or greater number of additional responsibilities. I realize that my feminist perspective may pull me toward literature that specifically looks at adult-child female caregivers to parents with dementia. However, doing so would cause me to overlook or exclude adult-child male caregivers whose experiences are just as valid and important to understand. I have mitigated this bias is by actively choosing to review literature that includes both male and female adult-child caregivers in the South Asian community.

Definition of Terms

Alzheimer's Disease: a condition in which certain cells in the brain become damaged which causes dementia symptoms. The condition worsens as time goes on, leading to a reduced capacity to retain new information, changes in behaviour, disorientation, and greater challenges with bodily functions including speech, movement, and swallowing (Alzheimer’s Association, n.d.a).

Caregiver/Caretaker/Carer: the terms, caregiver, caretaker, and career will be used interchangeably throughout this capstone, but they all refer to the same thing. A caregiver is someone who provides care to another person. In the case of dementia caregivers specifically, they may assist with tasks such as eating, hygiene, and medication among other tasks (Cramer, n.d.).

Dementia: an overarching term that refers to disease-caused impairment in the brain that results in changes to thinking (including memory), behaviour, and ability. There are a few different diseases that can present with dementia symptoms including vascular disease, Lewy body disease, and Alzheimer’s disease; the latter is associated with the majority of dementia cases (Alzheimer’s Association, n.d.a).

South Asian: refers to Individuals with Sri Lankan, Indian, Pakistani, or Bangladeshi ethnic origins (Statistics Canada, 2022).

Western Nations: According to Lyon (2020), when writers refer to "the West" they are often talking about nations that have adopted more of a "Western" culture, or way of viewing the world and operating such as being more individualistic. In contrast, countries operating within "Eastern" cultures tend to be more collectivistic. "Western" Nations can encompass Canada, the United States, a majority of Europe (with the exception of Eastern Europe, which may be included by some and not others), New Zealand, Australia, the United Kingdom, Switzerland, Norway, and Iceland. Conversely, "Eastern" countries may include those in Asia, the Middle East, Latin America, and Africa (Western Countries, 2024).

Outline of Remaining Chapters

The second chapter will consist of a non-exhaustive literature review. Information from the literature will be thematically organized and discussed to emphasize the importance of research on the lived experiences of South Asian adult children caring for parents with dementia. The final chapter of the capstone will consist of three parts: discussion, applied practices, and reflections on personal learning. In the discussion section, the purpose and aims of the project that were proposed in the first chapter will be revisited. It will include highlights of learnings and appreciation within the current knowledge. There will also be discussions on limitations in the current literature. The applied practices section will include recommendations for practice as well as a proposed idea that could be implemented to help better support South Asian adult-child caregivers with their mental wellbeing. The reflections on personal learning section will highlight insights gained as a result of writing the capstone.

Chapter Two: Literature Review

This chapter will explore the major themes found in the literature regarding the lived experiences of South Asian adult children providing care to parents with dementia in Western Nations including Canada, the United Kingdom, New Zealand, and Denmark. The discussion will be organized in terms of themes and subthemes that emerged during the review process. Systemic barriers faced by the family caregivers will be discussed first, including barriers within the healthcare system, language barriers, cultural barriers, and religion related barriers. Next, the lack of dementia awareness within South Asian communities with be explored including interpretations of dementia symptoms and diagnosis. Following this, the concept of filial duty will be delved into including what it is, and how it can impact support seeking in South Asian adult-child caregivers. A discussion about stigma felt by caregivers regarding their parent having dementia will follow. Then, the various ways in which becoming a caregiver has been found to impact different areas of adult-child caregivers' lives will be presented. This will be followed by findings in which the positive aspects of being a caregiver are explored. The chapter will conclude with a discussion of the experiences caregivers had with getting support from other family members and extended networks.

Systemic Barriers

Systemic barriers faced by South Asian adult-child caregivers seeking care for parents with dementia came up as a major theme in almost all the studies analyzed for this literature review. They have been organized according to three subthemes. The first subtheme that will be explored is barriers within the healthcare system which includes discussions of caregivers not getting adequate information, a lack of referrals to specialists, and delayed diagnosis for their family members with dementia. The second and third subthemes will delve into language, culture, and religion-related barriers which will encompass an exploration of the ways in which caregivers experienced a lack of linguistically, culturally, and religiously accessible and appropriate information and care support services. This will include discussions on subcultures, gender-matched care, discomfort with home care workers, and views on care homes related to culture.

Barriers within the Healthcare System

Jutlla and Arblaster's (2023) share the experiences of a male caregiver whose mother had been experiencing dementia symptoms for quite a while before her official diagnosis, which was delayed by almost a year after he consulted healthcare professionals with his concerns about her. The time between noticing symptoms and getting a diagnosis for family members was even longer for most caregivers in Hossain and Khan's (2019) study; it took anywhere from three years to a decade. Part of the late dementia diagnosis was due to family physicians not taking the behavior and bodily changes of the person with dementia seriously and attributing them to a normal part of aging (Hossain & Khan, 2019). Similarly, when carers in the study by Krishnamurthi et al. (2022) sought medical advice for their family members who were exhibiting dementia symptoms, physicians would dismiss their concerns and say that it had to do with age which led to late diagnosis.

Delays in having family members diagnosed was also due to the long wait times to see dementia specialists that were followed by a lack of follow-up (Krishnamurthi et al., 2022). Other caregivers who took their family members to see family doctors regarding concerns about dementia symptoms such as forgetting, sleep issues, and restlessness, were not referred to specialists at all (Islam & Akter, 2021). It is evident from these findings that doctors being dismissive of dementia related concerns was a common experience for South Asian families. This is unfortunate because it resulted in cases of late diagnosis which kept families unaware and uninformed about the dementia for much longer than they should have been.

Even when some caregivers raised concerns about dementia, family physicians were hesitant to send the patient for diagnosis (Hossain & Khan, 2019). Some caregivers in Hossain and Khan's (2019) study reported that their parents' diagnosis of dementia was discovered incidentally while receiving medical attention for something else. One participant, upon her mom's dementia diagnosis, realized that her dad who had since died, had also been experiencing the same condition; that participant found herself feeling resentful of the previous doctor who had dismissed her concerns in the past (Hossain & Khan, 2019). At the same time, learning that her mom had dementia provided her with some consolation (Hossain & Khan, 2019). This was not further expanded upon, but it would make sense if this participant found comfort in her mom's diagnosis as it would have answered questions that she may have been grappling with for years about the changes she had observed in both her mother and her late father.

When dementia was diagnosed, carers in the study by Krishnamurthi et al. (2022) which took place in New Zealand, felt that health care providers did not inform them well enough about the condition. This included not explaining interpretations of test results and scans and outlining the purpose and function of prescribed medications (Krishnamurthi et al., 2022). This likely put the caregivers in a place of disempowerment. Similarly, a participant in Jutlla and Arblaster's (2023) study conducted in the United Kingdom did not receive sufficient knowledge, advice, or guidance from medical professionals. As a result, he experienced difficulty with trying to learn about dementia and attempting to locate any support services that could be utilized (Jutlla & Arblaster, 2023). Another participant from the same study expressed that he was feeling lost after his mother's diagnosis for similar reasons: a lack of dementia education and referrals to supportive resources from doctors, leaving him no choice but to try and educate himself (Jutlla & Arblaster, 2023). In contrast to the unsupportive experiences with medial professionals however, there were some caregivers in the study by Krishnamurthi et al. (2022) who did feel like they had been helped. Those caregivers were able to access formal assistance with car rides when needed as a result of referrals from physicians, and they found this to be supportive (Krishnamurthi et al., 2022).

Islam and Akter's (2021) study showed that a large majority of caretakers did not know of other resources for dementia support outside of their family doctors, and did not have any awareness of non-medicinal approaches for treating symptoms; around half of these participants felt they would have benefited from being educated about dementia and taught how to care for a family member who has it. There were also adult-child caregiver participants in the study by Jutlla (2015) who felt that access to resources for South Asians with dementia and those caring for them while living in the United Kingdom were limited. One participant felt that this was partly because South Asians were not aware of resources, and without knowing about them, would not think to reach out and request them (Jutlla, 2015). The caregiver in this study felt that the medical professionals they were dealing with should have told them about these resources (Jutlla, 2015). The adult child participants in Jutlla and Arblaster's (2023) study also shared that their healthcare providers did not inform them about resources for individuals with dementia and their families. This made it difficult for them to know of additional services outside of medical care (Jutlla & Arblaster, 2023). Undoubtedly, many of the South Asian caregivers in these studies did not get the support they needed, which likely made the caregiving journey more difficult than it had to be.

The caregivers in the study by Hossain et al. (2022) did not feel well supported by external support services that were available as they were costly and lengthy wait times made them less accessible. The authors did not go into detail about what exactly these external services were, which is a limitation because it would be helpful to know the areas in which improvement is needed and where mental health professionals could perhaps provide extra support. They also shared that there was a lack of assistance within the system for their family member with dementia, including end of life related planning (Hossain et al., 2022). They wished for more support outside of being told that dementia was incurable and that nothing could be done about it (Hossain et al., 2022). However, not every participant had a negative experience with the healthcare system in the United Kingdom. There were caretakers who spoke highly of healthcare staff and seemed appreciative for the support they provided (Hossain, 2021).

Language Barriers

A little over fifty percent of participants in a study by Herat-Gunaratne et al. (2020) were accessing care services that were provided in the home; however, the families who had support workers who did not speak the same language as the person with dementia experienced language barriers that made receiving care more difficult. Related to this, when there was not a linguistic match between home support workers and the family member with dementia, the perception was that the care provided was not as adequate as it could have been (James et al., 2023). The South Asian caregivers preferred that home care support workers be able to speak the same language as their family for better communication; however, this was not always possible (James et al., 2023).

Other caregivers were reluctant to even attempt to use care support services, partially because of the perceived language barriers due to an insufficient availability of support workers who spoke South Asian languages (Nielsen et al., 2021). Additionally, not having access to inclusive resources such as pamphlets in South Asian languages made it difficult for caregivers to gain a full understanding of the condition (Jutlla & Arblaster, 2023). It is clear from these studies that having care workers who would be able to communicate with the person with dementia in their first language was of high importance for many family caregivers. Moreover, having access to informational materials in South Asian languages would be supportive for caregivers who also may not have high English proficiency to better understand dementia.

Two thirds of the participants in Islam and Akter’s (2021) study conducted in Canada expressed that they had an English language barrier. Although this was not explicitly stated as a barrier to getting informational and hands-on support with caregiving, it is highly possible considering that the participants had little awareness of dementia overall. This lack of knowledge included not knowing how they could best provide care (Islam & Akter, 2021). This could be because many informational resources in Canada tend to cater to English speakers, and English is also the language one often needs to speak with medical professionals and support staff. This also appears to be the case in the United Kingdom. James et al. (2023) learned from participants in their study that online resources were primarily available in English. Moreover, a participant in Jutlla and Arblaster's (2023) study also conducted in the United Kingdom, shared how challenging it was to try to find resources to support her mother who had little to no English proficiency. Another participant in the same study said the majority of resources were in English, that extra effort was required to try and access them in other languages, and that those who had minimal English proficiency would have greater difficulty obtaining them (Jutlla & Arblaster, 2023). She also felt that the lack of resources readily available in languages other than English was a form of systemic discrimination and said it made her feel unwelcome in the United Kingdom despite living there for many years (Jutlla & Arblaster, 2023). Indeed, individuals of South Asian origins (India, Pakistan, and Bangladesh) composed the second highest ethnic population residing in the United Kingdom after White British individuals as per the 2021 census (GOV.UK, 2024).

A need for translators came up as a theme in several studies. When caregivers in the study by Hossain et al. (2022) were in the process of planning for the end of their parents' lives, they faced language barriers trying to share what they wanted and expressed that having translators would have been supportive. The immigration experiences of caregivers were not mentioned by Hossain et al. (2022), which is a limitation as it would have provided greater insight into the need for translators. However, one can surmise that the participants were not proficient in English and had perhaps immigrated to the United Kingdom in adulthood. A lack of translators was also something that the participants in the study by James et al. (2023) experienced. The authors learned from participant interviews that language was one of the primary barriers to accessing dementia related support because translators were not available at all dementia care and resource centres (James et al., 2023). When translators were available, they did not always speak the particular South Asian language that the individuals accessing support needed (James et al., 2023). This finding brings awareness to the fact that although dementia care services might have translators with South Asian ethnic origins, they may not be able to speak all South Asian languages. Worries about family members with dementia feeling isolated due to language barriers and lack of translators also came up for caregivers when reflecting on whether care homes could be an option (Krishnamurthi et al., 2022). Similar concerns about language barriers for the person with dementia also prevented caregivers in the study by Nielsen et al. (2021) from considering long-term care facilities.

Culture and Religion-Related Barriers

Sub-cultures. James et al. (2023) found that while some services catered to South Asian families dealing with dementia in the United Kingdom, they were not always available for the particular sub-cultures to which the families belonged. Not all South Asians are connected with other South Asian cultures or religions outside of their own. Therefore, these resources were not preferrable for those who were not part of the dominant South Asian subcultural groups in a particular area (James et al., 2023). James et al. (2023) gave an example of a Bangladeshi woman who followed the Hindu religion; she did not end up accessing the Bangladeshi day centre near her home because the majority of people there were Muslims. This meant that they were a part of a different Bengali subculture than she was, and she did not resonate with this sub-culture (James et al., 2023).

Some participants felt that if support workers came from the same religion as the person with dementia, they would have a better understanding of what might be needed in terms of care; for example, a culture and religion specific diet for the person with dementia (James et al., 2023). For some caregivers, knowing that their family members with dementia would not be provided with culture specific food was a barrier to utilizing external services (Herat-Gunaratne et al., 2020). They felt that there was a lack of awareness and respect of these factors amongst non-South Asian care support staff (Herat-Gunaratne et al., 2020).

This section brings awareness to the fact that there are different subcultures within overall South Asian culture; individuals with different languages, practices, and beliefs have differing needs. It is also a reminder that even within the subcultures themselves, there can be differences such as religion as demonstrated by the example of the Bangladeshi woman not fitting in at a day centre even though she too was Bangladeshi (James et al., 2023). This is relevant to the lived experiences of caregivers with parents with dementia because the less accessible external care services are, the more in-home care adult children will likely need to take on, depriving them of time that they could use on taking care of themselves or other parts of their lives.

Gender-matched Care. There were some people with dementia who felt uncomfortable with care staff of a different sex seeing certain parts of their bodies uncovered. This was related to their cultural and/or religious beliefs, so families preferred that care staff be of the same sex as the person with dementia (Hossain et al., 2022). James et al. (2023) also reveal how important it was for caregivers that the gender of support workers match with the gender of the parent with dementia. When families had care staff from other cultural backgrounds who did not have an understanding of these factors, the care was perceived as negative by the family caregivers as the person with dementia would become upset (Hossain et al., 2022). Having to deal with a parent with dementia becoming upset would likely not be easy situation for adult children to manage and would probably make caregiving more difficult. Additionally, having to explain cultural norms or practices to support workers would require adult-child caregivers to be present when care was happening, spending time ensuring care is done in a way that does not cause discomfort or distress to the parent rather than using that time to take a break from caregiving. Additionally, there were certain care tasks that support workers assumed male adult children would be okay with doing for their female parents which were in misalignment with cultural norms and became barriers to accessing these resources (Herat-Gunaratne et al., 2020).

Discomfort with Home-Care Workers. Although some participants in Hossain's (2021) study did utilize home care services for their family member with dementia, most of them did not feel comfortable being away while the care was happening; they worried that the care would not be completed in accordance with sensitivity to and understanding of cultural and religious factors. Based on the interview excerpts included in Hossain's (2021) study, it appeared that caregivers felt the need to direct external care staff, especially when they were providing care related to hygiene after the person with dementia had bladder or bowel movements. Instead of just wiping the associated areas of the body, the caregivers wanted the cleaning to be done according to South Asian cultural norms of washing using water (Hossain, 2021). Similarly, James et al. (2023) revealed that some South Asian adult-child caregivers were not sure if they could trust home care workers to help their parent with dementia. One South Asian daughter from a Bangladeshi background said she felt that she would need to be present and watch the care when it was happening (James et al., 2023). Due to mistrust, many participants revealed they would rather have another family member provide support with care if possible (James et al., 2023). There were also participants in Jutlla's (2015) study who were caring for parents who did not feel comfortable with home support workers helping them with bodily care tasks; therefore, the caregivers felt they needed to manage these on their own. The authors did not go into detail about why the parents with dementia felt discomfort. Was it for reasons similar to those discussed in the previous section regarding gender and lack of cultural awareness? Having this additional information would have provided greater insight. In contrast, the caregiver participants in the study by Krishnamurthi et al. (2022) found home care resources to be very helpful in providing them with some relief in the day-to-day care tasks of their family member with dementia. Other carers did not receive the services that would have helped them through publicly available resources, so they resorted to paying out of pocket; for example, paying for house cleaning support (Krishnamurthi et al., 2022).

Views on Care Homes in Relation to Culture. Most carers in the study by Krishnamurthi et al. (2022) took care of their family member at home and were opposed to placing them in a long-term care facility. This was partly because the idea of sending a family member to a care home was not in alignment with Indian cultural values (Krishnamurthi et al., 2022). Similarly, the adult-child caregivers in the study by Herat-Gunaratne et al. (2020) had minimal consideration of long-term care homes as they were viewed as individualistic and not culturally inclusive; participants perceived care homes as mainly serving those who identify with western culture (Herat-Gunaratne et al., 2020).

Neisen et al. (2021) discuss how caregivers were reluctant to place their family member in long-term care facilities as they viewed them as inaccessible due to cultural barriers. The specific cultural barriers were not mentioned, however, which would have provided a greater understanding of South Asian needs in care homes. Similarly, participants in Hossain's (2021) study reported that care facilities were not inclusive of religious and cultural factors. It was this perception that led most family caregivers to decide to mainly provide care on their own at home (Hossain, 2021). Many caregivers in the study by Krishnamurthi et al. (2022) were also opposed to care homes due to concerns about lack of culture inclusive diets i.e. Indian vegetarian. Contrary to the caregivers who did not consider care homes at all, others shared that they would be more open to them if greater cultural elements were to be incorporated that would engage the brains of their family members; this included having areas for praying and Indian games that the family member may enjoy (Krishnamurthi et al., 2022).

These findings highlight how important it is for South Asian families that care facilities be culturally inclusive by accommodating religious practices, cultural foods, and cultural activities. It also brings attention to the fact that inclusive practices are not currently practiced, which places a greater burden on adult children to provide all care for their parents at home when that may or may not be what is ideal for them. This is important for mental health professionals who are working with South Asian caregivers to understand so that they can be culturally sensitive of the needs of South Asian client families, and aware of the types of services that may or may not be suitable and why.

Herat-Gunaratne et al. (2020) discuss a belief that the family member's health would more quickly decline if they were to start living in a long-term care facility. This finding was not expanded upon, but it would have been interesting to understand the origin of this belief. What was it about care facilities that made adult children believe their parent’s health would decline faster there than if they were to continue living at home? Is this a common belief amongst the South Asian community? Having insight into this would be supportive for counsellors working with adult children reluctant to utilize care homes for their family members with dementia.

Perceptions of Discrimination and Implied Assumptions about Culture. The participants in Hossain’s (2021) study shared that they had overall negative experiences with public support services, such as home care workers and financial assistance. These negative experiences caused them great stress, frustration, fear, embarrassment, and shame, making them reluctant to access these supports. Negative experiences cited in the United Kingdom included racial discrimination and stereotyping which caretakers felt was purposefully done because they belonged to minority groups in the United Kingdom (Hossain, 2021). There were times when caretakers felt that they were put in uncomfortable positions where they had to justify why they were unemployed and needed housing support or financial assistance; they were met with disregard and a lack of empathy or understanding, and were indirectly accused of using their family member’s condition as an excuse to receive financial support from the government (Hossain, 2021).

Some caregivers in Hossain’s (2021) study also shared that home support staff were disrespectful and hostile toward them during communications, and that they provided care for much shorter periods of time than what was obligated. There were also caregivers who felt that they and their family members were treated poorly in medical settings due to their race; one participant felt that healthcare staff were purposely neglecting his parent in the hospital by leaving him on the floor for extended periods of time after falls (Hossain, 2021). South Asian caregivers also reported their perceptions of white British families being prioritized in terms of receiving formal care support compared to minorities (Jutlla, 2015). These two studies indicate that South Asian caregivers in the United Kingdom felt they were treated unequally due to their ethnic backgrounds. It is important to know that systemic barriers can include perceptions of discrimination which can lead to a reduction in service usage by South Asian caregivers, and likely additional mental distress on top of the struggles they might already be managing.

Some memory clinic doctors (non-South Asian) interviewed in the study by James et al. (2023) shared that based on their experiences with South Asian families, it seemed that they wanted to provide full care to the person with dementia at home; the memory clinic doctors also felt that the large family networks in the South Asian community allowed them to do this without needing external support resources (James et al., 2023). While this may be true for some South Asian families, it may not be the case for all, and that is where this blanket assumption could be problematic. In some cases, South Asian caregivers may be reluctant to involve other family members with providing care due to not wanting to burden them and therefore would want external care support (James et al., 2023). Alternatively, the person with dementia may prefer that non-family members assist them with certain tasks which would also warrant the need for care support staff (James et al., 2023).

Along similar lines, Herat-Gunaratne et al. (2020) found that if adult children began living with a parent who had dementia, external care organizations decreased the hours of support they provided, which made caring more difficult and burdensome for adult-child caregivers; one participant perceived this as being a form of punishment, but assured himself that he would find a way to provide care himself since it was his own parent (Herat-Gunaratne et al., 2020). Could assumptions related to South Asian culture and caring for one's parents in their later years of life have played a role in the decision to cut hours of service? The authors did not delve further into this with participants; however, it would be interesting to explore. If this were the case, it would be problematic as not every South Asian adult child necessarily wants to take on the role of primary caregiver to a parent with dementia, despite cultural norms or expectations. And when hours of service are decreased, it may give these individuals the implicit message that it is their responsibility to be the main caregiver for their parent, reinforcing the message they may already receive in the South Asian community that they may or may not agree with. This could add to the burden and pressure that some South Asian adult caregivers already feel.

Lack of Dementia Awareness

In around half of the articles examined for this literature review, the theme of South Asian adult-child caregivers lacking awareness about dementia came up. While all the caregivers noticed changes in their parent, the idea that the changes could be related to dementia was not the first thought for the majority. More details from research studies highlighting and explaining lack of dementia awareness in the South Asian community are outlined below.

Not Knowing What Dementia Is

When the symptoms of dementia first appeared, family caregiver participants in the study carried out by Hossain et al. (2022) did not recognize them as being dementia-related because this condition was not something that most caregivers had any knowledge or understanding of. They could tell that something was off but were not sure exactly what (Hossain et al., 2022). Symptoms included the family member with dementia experiencing a loss of memory, becoming more aggressive, changes to personality, wandering off, forgetting names, and keeping to themselves more (Hossain et al., 2022). Similarly, caregivers in the study by Hossain and Khan (2019) noticed various symptoms including hallucinations, being confused, forgetting, incontinence, differences in personality, and experiencing delusions prior to reaching out for support. Because family members did not know what dementia was or what symptoms to look for, it took most caregivers several years before they were able to get their family member diagnosed; they only learned about dementia once the diagnosis was made (Hossain & Khan, 2019). Based on these findings, diagnosis delay was in part due to the family caregivers not being able to recognize changes as being dementia symptoms right away. As was discussed in the barriers within the healthcare system section, diagnosis was further delayed by medical professionals not taking concerns reported by family members seriously.

Comparably, prior to diagnosis and developing concern for the health of their family members, many of the caregivers in the study conducted by McCleary et al. (2013) failed to recognize that the initial changes they were witnessing were dementia symptoms. Some of these included family members having trouble finding their way home and not remembering names or where certain objects in the house belonged (McCleary et al., 2013). Caregivers did not realize the severity of their family members' condition until they symptoms progressed, which for some was after a different medical issue occurred such as complications after a surgery (McCleary et al., 2013). The majority of participants in the study by Krishnamurthi et al. (2022) were not even sure what dementia was and only understood what the researchers were asking about once they shared some of its common symptoms such as forgetfulness. This brought attention to the fact that there is no direct translation for the word dementia in Hindi or Fijian Hindi, which were the primary languages spoken by the participants (Krishnamurthi et al., 2022). This may be the case for other South Asian languages too.

Additionally, a great number of participants in Islam and Akter's (2021) study appeared to have minimal awareness of dementia in general including what exactly it was, the risk factors that could make it more likely to happen, prevention strategies, treatment approaches, the types of providers they could go to for support, or how they could adequately support the person with dementia and themselves. Likewise, for the participants in Jutlla and Arblaster's (2023) study, it was found that there was minimal awareness about dementia in the South Asian community in the United Kingdom. This put adult-child caregivers in a position where they had to teach themselves about the condition through online resources while caregiving for their parent and teaching other family members about it (Jutlla & Arblaster, 2023). Similarly, participants in Hossain and Khan's (2019) study, also conducted in the United Kingdom, engaged in self-learning upon having the diagnosis of their family member become official. Caregivers took the initiative to attain knowledge about dementia through books and websites, and gaining a better understanding of the condition helped their stress levels to go down (Hossain & Khan, 2019).

These are significant findings that are highly relevant to the field of counselling. They bring awareness to the fact that having more knowledge about conditions like dementia, especially for adult-child caregivers, can provide great relief and help to improve mental health by decreasing stress. It is also an important reminder to not assume that every client will know what dementia is, because it could result in missed opportunities to help. Counsellors could support clients going through the beginning stages of the caregiving journey by either having knowledge about dementia themselves or knowing about accessible resources that could be supportive and empowering to clients. Gaining this awareness and information would allow caregivers to become more vigilant of changes within their family members and to be prepared with steps they could take to help both the person experiencing dementia and themselves.

Interpretations of Dementia Symptoms and Diagnosis

The interpretations of the causes of dementia symptoms ranged from study to study and from one participant to another even within the same studies. Some participants believed dementia was given to their family member by a higher power (Hossain & Khan, 2019; Hossain et al., 2022). Along similar lines, other caregivers felt that experiencing dementia was a part of the person's fate, a belief that comes from the Hindu religion (Krishnamurthi et al., 2022). It was not said in these studies whether these beliefs led to positive feelings surrounding dementia or negative ones, but it would have been beneficial to explore to get a better idea of how it affected the caregivers' mental health. A quarter of the caregivers in the study by Hossain et al. (2022) shared that when symptoms were first noticed, they believed that the family member with dementia was behaving in certain ways on purpose. This lack of understanding about why a family member is acting a certain way would likely lead to feelings of confusion and frustration and possibly make things worse in the relationships between the person with dementia and their family members.

Some caregivers believed that depression, or even diabetes could have led to dementia (Hossain & Khan, 2019). There is evidence in the research to support these connections (Cantón-Habas et al., 2020; Wiels et al., 2020). Similarly, a large portion of caretakers in Islam and Akter's (2021) study felt as though depression and anxiety increased the likelihood of dementia occurring, and the research does indeed indicate a link between anxiety and dementia (Kuring et al., 2020). The caregivers in the study by Krishnamurthi et al. (2022) viewed dementia as brain and body deterioration, and believed this was due to feeling lonely as a result of immigrating, going through other hardships, or not receiving enough mental or physical stimulation. Loneliness has been found to increase the risk of dementia according to the existing research (Sutin et al., 2020), and there is also research indicating that a lack of mental stimulation can increase the risk (Kivimäki et al., 2021). Going through difficult times in life might coincide with depression and/or anxiety.

There were also, however, some false perceptions amongst caregivers, such as thinking that the condition was contagious and a threat to life which caused them anxiety about potentially catching it themselves (Hossain & Khan, 2019). Others believed perhaps the symptoms were the result of black magic (Hossain et al., 2022), a belief that exists in South Asian culture (Hussain et al., 2024). The feelings experienced by caregivers who suspected black magic were not explored by the authors; however, it is safe to say that they were likely not comforting. One of the most significant myths that was believed as truth by caregivers in several studies was that dementia symptoms were normal for the elderly. A large portion of caregivers in the study by Hossain et al. (2022) thought memory issues were to be expected with older age. Participants in the study by Krishnamurthi et al. (2022) also described the condition as being a normal part of getting older. Similarly, caregivers in the study by McCleary et al. (2013) thought that forgetting more was a typical part of aging which led to a diagnosis delay. For other caregivers, viewing dementia symptoms as an inevitable part of ageing prevented them from believing that medications could help their family member (Islam & Akter, 2021).

Existing beliefs about the causes of dementia, especially the misconceptions, are important to know for mental health practitioners, as they could help to dispel myths for clients. They could do this by providing them with factual information about dementia or by directing them to the appropriate resources. This could help to not only reduce any negative feelings such as worry, fear, or anxiety for caregivers who might fear dementia is contagious or that black magic was involved, but it could also encourage them to seek medical support for their family member sooner. If caregivers have already connected with medical doctors but have not been taken seriously, mental health professionals could help empower them to advocate for their family members.

Sense of Filial Duty

Several of the studies examined for this literature review mentioned filial duty as one of the primary motivating factors for South Asian adult children becoming their parents' main caregivers and providing care at home. The concept of filial duty or filial obligation exists in many Asian cultures in which children grow up learning that one must care for their parents as they become older and require support (Cicirelli, 1993). This section explores how South Asian adult children experience filial duty with regard to the role of becoming a caregiver to a parent with dementia.

The adult-child caregivers in the study conducted by Herat-Gunaratne et al. (2020) experienced a strong filial duty to provide care for their parent with dementia at home which they described as coming from South Asian cultural norms. They shared that this fell under the cultural expectation of caring for one's parents in their later years of life as a way of giving back for the years their parents provided care for them while growing up; it was also what many of the participants witnessed their parents do for their own parents (Herat-Gunaratne et al., 2020). Similarly, the majority of family carers in the study by Nielsen et al. (2021) chose to care for parents with dementia at home so that they could fulfill their filial duty. They described it as a responsibility, a way of repaying their parents for their care, and an expectation in their cultures (Nielsen et al., 2021). Likewise, the adult-child carer participants in the study by Krishnamurthi et al. (2022) took it upon themselves to take care of their parents at home. They viewed this as their filial duty which they were expected to honour (Krishnamurthi et al., 2022). Based on these findings, it seems that filial duty was a strong motivator for many adult children to become at home caregivers to their parents with dementia. The next section explores how this sense of obligation as well as stigma became barriers to reaching out for additional support.

Filial Duty and Stigma as Barriers to Seeking Formal and Informal Support

Adult-child caregivers in the study by Herat-Gunaratne et al. (2020) felt that the cultural norms and expectations to care for one's parent without external help made it harder for them to seek out support services even if they wanted to; this was because in the South Asian community, handling care without utilizing any formal support services was viewed as something to be proud of. Similarly, the adult-child carers in the study by Nielsen et al. (2021) were very reluctant to use external support, partly due to these cultural values of family caring. Some of these participants felt obligated to provide care for their parent with dementia and felt guilty if other family members were to shoulder more of the burden (Nielsen et al., 2021).

Along similar lines, some caregivers were also wary about reaching out to their extended family members and friends for care support such as those the study by Hossain et al. (2022). The adult-child caregivers shared that their hesitation was due an expectation in their culture to take responsibility for providing care to their parents, therefore reaching out for extra help came with stigma (Hossain et al., 2022). Similarly, the carers in the study by Krishnamurthi et al. (2022) opted not to get support from extended family members or to place their parents in a care home because of their felt sense of filial duty to provide all care by themselves. Likewise, a sense of filial duty as a barrier to utilizing external support was implied in the study by James et al. (2023); a female adult-child caregiver did not feel that her father would be okay with anyone caring for him except for her so she decided that if his condition got to the point where he needed more care, she would be the one to provide it without external support (James et al., 2023).

The perceived stigma of not caring for a parent with dementia on one's own at home also came up in the study by Nielsen et al. (2021) as participants shared that not doing so would be looked down upon in the community. One participant shared that this sense of duty was rooted in religion (Islam in this participant's case) in addition to culture (Nielsen et al., 2021). Religion also seemed to have an influence on the sense of responsibility to provide care to one's parent at home for the caregivers in Hossain and Khan's (2019) study who also followed Islam.

Alternatively, there were some adult-child caregivers who primarily utilized extended family, friends, and even those living in the same neighborhood as extra support resources for providing care (Herat-Gunaratne et al., 2020) and experiencing stigma around doing so was not mentioned. This is a good example of how certain cultural concepts even those as prevalent as that of filial duty existent in South Asian culture, can impact individuals coming from the same or similar cultures differently. To make the assumption that an adult-child caregiver would be willing and comfortable to reach out for extra support from family and friends within the South Asian community could result in ruptures in the therapeutic relationship.

While many caregivers felt discouraged from seeking extra support due to cultural norms and expectations, there were also some who felt that receiving professional assistance as well as being able to connect with other caregivers could have been helpful (Herat-Gunaratne et al., 2020). This would be important to know for mental health professionals supporting South Asian adult-child caregivers; even though filial duty can act as a barrier to seeking outside support, it does not mean that the support is not needed and would not be appreciated. It also indicates that South Asian caregivers may benefit from meeting other South Asian caregivers who could share in their experiences.

Experiences of Dementia Associated Stigma

A majority of the caregivers in the study by Hossain et al. (2022) expressed that within the South Asian community, speaking about dementia and letting others know that their family members were dealing with it was avoided; they said this was because of the stigma and shame associated with mental health or brain functioning issues. The participants feared that others would think the person had “gone mad” (Hossain et al., 2022, p. 9). Similarly, a significant portion of the family carers in Islam and Akter’s (2021) study associated shame or stigma with dementia and therefore chose to keep their family members’ condition a secret from extended family and neighbors. They were afraid that their family member would be made fun of and worried that there would be gossip (Islam & Akter, 2021). Moreover, a very small minority of participants in Islam and Akter’s (2021) study were willing to go with the person with dementia to receive medical treatment and/or care. It was not said why this was the case, but it begs the question, was it because of the stigma or shame around dementia in the South Asian community? Additionally, over half the participants in that same study said they would not seek medical attention or obtain diagnosis if they were at risk or had suspicions of dementia development (Islam & Akter, 2021). This avoidance of medical attention may also be stigma related and if so, it would indicate that stigma may act as a barrier to caregivers seeking preventative care which would have impacts on their overall wellbeing.

Conversely, the participants in Hossain and Khan’s (2019) study stated that they did not experience any stigma surrounding their family member’s dementia symptoms within the Bengali community, and that people were instead understanding and offered their support. Hossain and Khan

(2019) do mention though, that it is possible that those who did associate significant stigma with dementia may have chosen not to participate in the study, and this is a valid point. Additionally, the sample size was quite small with a total of six participants. Therefore, the results suggesting that stigma may not exist around dementia in the Bengali community could be misleading. Knowing that dementia related stigma is something that caregivers of South Asian ethnic origins may struggle with is highly relevant for mental health practitioners who could support them through the accompanying feelings and experiences.

Impacts of Becoming a Caregiver on Different Areas of Life

This section of the literature review explores the impacts of becoming a caregiver on different areas of life including mental health, physical health, career, finances, social life, and relationships. Flowing from the impacts to mental and physical health sub-section, there will be discussions on adult children as the preferred caregivers, the influence of immigration on stress levels and resiliency, loneliness due to lack of community awareness, and grief experiences including role change/reversal. This section provides the most insight into the lived experiences of South Asian adult-child caregivers to parents with dementia in terms of how it impacts their day to day lives and sense of self which is highly relevant to the field of mental health.

Impacts to Mental and Physical Health

Stress, worry, guilt, depression, burden, frustration, and social isolation were some of the major feelings that came up for adult-child caregivers, with some experiencing thoughts of suicide. In some cases, the mental health struggles were also accompanied by physical symptoms. These experiences are discussed in more detail below.

Much of the mental burden seemed to come from the caregivers' concern for the safety of the person with dementia which they attempted to alleviate by keeping a close eye on the family member as much as possible. It was found that participants in the study by McCleary et al. (2013) experienced a decline in their mental well-being as a result of witnessing their family members with dementia behave differently than they did before having dementia, including putting their physical wellbeing at risk; the caregivers felt concerned, frustrated and depressed. Similarly, carers in the study by Krishnamurthi et al. (2022) experienced feelings of stress as their parents with dementia began to require constant monitoring and assistance with day-to-day activities. This included close supervision when the parent was bathing or walking in case of falls, cooking food for the parent, and reminding them to have meals, to turn cooking appliances off, and to take medication (Krishnamurthi et al., 2022).

Other factors also contributed to the feeling of burden while in the caregiving role. This included adult children having to spend much of the day at home looking after the parent with dementia, while having a lack of information and care support, and managing other aspects of their lives (Jutlla & Arblaster, 2023). This made caregivers feel socially isolated and decreased their mental well-being (Jutlla & Arblaster, 2023). Adult children feeling a duty to provide care for parents at home itself was enough to induce feelings of burden and guilt (Herat-Gunaratne et al., 2020) which made it difficult to manage. This relates to earlier discussions of filial duty and the corresponding expectations. These struggles warranted the need for mental health support from professionals as one adult-child caretaker expressed (Herat-Gunaratne et al., 2020). Caregivers also experienced high levels of stress while in the role; one participant providing care to her dad feared that the stress could lead to her cancer returning (Jutlla, 2015). Moreover, being a caregiver was not what all adult children had wished to become. The majority of family carers in Islam and Akter's (2021) study said that they did not actually want to be carers, with one participant stating that it was burdensome (Islam & Akter, 2021).

The caregivers in Hossain's (2021) study shared that physically, the caregiving role was tiresome, taxing, and demanding which could lead to feelings of great unhappiness at times. Like the findings in some of the aforementioned studies, the role required helping the person with dementia with day-to-day essential tasks, such as eating, changing diapers, and continual supervision among other caretaking tasks, many of which had to be done at the same time (Hossain, 2021). The majority of participants in Hossain's (2021) study felt that being a caregiver to a family member with dementia was similar to and in most cases harder than taking care of an infant; some participants had to lift their family member to provide hygiene care which was strenuous on their bodies and exacerbated their own existing physical health problems (Hossain, 2021). Additionally, caregivers often found themselves waking during the night every time the family member with dementia would wake, which caused them to have disrupted sleep and fatigue during the day (Hossain, 2021). Having reduced or lower quality of sleep would inevitably impact the mental wellbeing of caregivers. Indeed, Ae-Ngibise et al. (2015) found that sleep issues as a result of caregiving are connected to greater feelings of burden.

Adult Children as the Preferred Caregivers. When adult-child caregivers made attempts to obtain formal support with caring for their parent with dementia, many parents did not welcome it and wanted their children to take on all care. Herat-Gunaratne et al. (2020) found that around fifty percent of the caregivers in their study took the steps to access external supports for help with dementia care in the home; however, not all were able to successfully receive it. This was mainly because the parent with dementia would have a preference and implied expectation for their own family members (usually an adult-child or adult child-in-law) to take care of them instead (Herat-Gunaratne et al., 2020). This strong preference often led to the parent with dementia making it clear to support workers that their assistance would not be needed since the adult children were there and could do a better job (Herat-Gunaratne et al., 2020). Understandably, this would have led to families ceasing to use these services since the parent was not cooperative.

Adult-child carers indicated that they could have benefited from the help provided by support workers, and that their parents not being open to utilizing these services placed a greater burden on them to take on all the work (Herat-Gunaratne et al., 2020). Some of the adult-child caregivers in Jutlla's (2015) study also could have been aided by external support services. They attempted to use them, but they were not able to ease their caregiving burdens because their parents with dementia did not want to access any day centres or receive any other sort of external support (Jutlla, 2015). This made it so that the adult children were the ones having to take on all the caregiving tasks which left very little time for themselves (Jutlla, 2015).

These findings further expand upon what was discussed in a previous section about why adult-child caregivers in the South Asian community tend to spend the majority of their time at home caring. Not only is it because of their desire to make sure their parent does not get hurt, but it is because the parent may also have the expectation that their adult child can, should, and will be able to take care of everything. As discussed previously, filial duty likely plays a heavy role in this expectation.

Influence of Immigration on Stress Levels and Resiliency. When analyzing the literature, it was found that immigration experiences tended to have an impact on how resilient and thus how mentally healthy caregivers were. The following section will explain this in more detail. All the adult-child caregivers in the study by Jutlla (2015) who were born in the United Kingdom or immigrated in childhood experienced more stress due to lower levels of resiliency compared to those who had immigrated in adulthood either from rural Punjab or East Africa. These caregivers felt pressure from older individuals who had immigrated in adulthood to accept their caregiving role and to be just as resilient as them (Jutlla, 2015). Those who had immigrated later in life made those who were born in the United Kingdom or immigrated there as children feel as though their struggles were not as difficult as they made them out to be and expected them to cope well (Jutlla, 2015). This caused those who had spent all or most of their lives in the United Kingdom to experience loneliness, high stress, invalidation, and a lack of empathy and support (Jutlla, 2015). The decline in mental health also included depression, suicidal ideation, and near attempts for some (Jutlla, 2015).

One participant who immigrated to the United Kingdom as a child said that she experienced significant stress as a result of being a caregiver to her father-in-law (Jutlla, 2015). However, she felt she could not complain when she compared herself to older Indians who she perceived as being more resilient due to their difficult life circumstances (Jutlla, 2015). This caregiver felt that she or her children could never exhibit that level of strength because they grew up in the United Kingdom (Jutlla, 2015). In contrast, however, another participant in Jutlla's (2015) study who was born in the United Kingdom coped better than other Britain born participants in terms of stress despite living with just her mother and having no assistance from relatives. This was attributed to her experience of immigrating to Germany previously, living there for two decades and then returning to the United Kingdom to provide care for her mom at home (Jutlla, 2015).

It appears that those who went through immigration related struggles in adulthood were able to use those experiences to better handle the challenges that came with being a caregiver to a parent with dementia. In contrast, those who had not had such struggles coped more poorly. This implies that the experience of immigration in adulthood for a South Asian person is much more difficult than it would be for someone who immigrated as a child. This is important for mental health professionals to be aware of, while keeping in mind that the experiences of each South Asian caregiver will be unique regardless of immigration experiences or lack thereof and will not necessarily be in line with the results of the Jutlla (2015) study.

Loneliness Due to Lack of Community Awareness. A participant in Jutlla and Arblaster’s (2023) study shared that learning of her mother’s diagnosis was hard to accept due to not having awareness of the condition beforehand. She also felt alone in her journey as an adult-child caregiver because the South Asian community she was part of did not seem to know about dementia (Jutlla & Arblaster, 2023). Another participant in the same study described his experience of transitioning into the role of a caregiver for his mother as exhausting and lonesome. He shared that he felt this way because not only did he have to teach himself about the condition while learning to be a caregiver, but he also had to try and explain it to others in the South Asian community who also did not previously know what it was; this caused him to experience feelings of fearfulness for what was to come (Jutlla & Arblaster, 2023). The feelings of fearfulness were not explored, but it would have provided a greater understanding of the thoughts that can go through the minds of individuals shifting into the role of caregiver for a parent with dementia. Moreover, this participant felt that as a male, it would be difficult to share the emotions he was experiencing with other males (Jutlla & Arblaster, 2023). This likely added to the participant's feelings of loneliness, because not only did he feel that the general South Asian community would not be able to understand his experience, but he also was reluctant to share his struggles with other males, which seems like something that would have been supportive for him.

Grief Experiences Including Role Change/Reversal. The changes adult children witnessed their parents go through once the dementia began took a toll on their mental health; they felt like their parent was no longer the same person they once knew (Hossain, 2021). Adult-child caregivers also experienced a role reversal with their parent (Hossain, 2021) Prior to the dementia, their parent was someone to whom they could go for support and protection, but after becoming caregivers, they viewed themselves in a parental role; the parent felt like their child who needed their physical and emotional support (Hossain, 2021). Similarly, adult-child caregivers in Hossain and Khan's (2019) study described their parents becoming child-like and felt like they had become their parent. It would make sense for adult children to experience a sense of grief throughout this process because the role the parent used to play for them, such as one of guidance, had been taken away by the dementia.

Throughout the grief, were also experiences of loneliness and worries about judgment. Adult children struggled alone with their parents' medical treatment ending when it was no longer effective, and the parent was at the end stage of life (Hossain et al., 2022). They would refrain from sharing this with other family members in fear that they would struggle to accept it and hold them responsible for the decline in health (Hossain et al., 2022). The authors did not explore how the caregivers felt while going through experiences like this which is a limitation because it would have provided greater insights into their lived experiences. One could imagine, however, that having to make such a big decision regarding the life of one’s parent and then feeling the need to hide it from other family members could bring up complicated feelings including anticipatory grief, stress, pressure, guilt, and a feeling of aloneness through it all. Adult-child caregivers also felt alone and helpless as they watched their parent deteriorate to the point of death, and it affected other areas of their lives profoundly (Hossain, 2021). One participant shared that during the initial grieving period, he went through immense anguish and depression, which left him feeling debilitated (Hosain, 2021).

Related to death and dying, adult children were hesitant to complete legal processes related to their parents' impending death such as discussing wills; they feared that doing so may result in them being misperceived as selfish (Hossain et al., 2022). Knowing that this stigma can exist for caregivers to parents with dementia in the South Asian community is important because not having these pieces in place prior to the death of one's parent could cause great distress. This would warrant the need for support throughout this process, which a mental health professional could provide.

It was also found that South Asian adult children experienced difficult emotions as they navigated honouring their deceased parents’ wishes of wanting their ashes or bodies to be buried or scattered in the South Asian countries they had been born in (Hossain et al., 2022). Some worried that the bodies of their parents would not be transported with care and would be in worse shape after the journey to South Asia; this brought up feelings of overwhelm, anxiety, and uncertainty about whether to go forward with what the parent wanted. Mental health professionals could provide emotional support to individuals throughout this process.

Impact on Career and Finances

Several of the adult children in the examined studies significantly altered their employment situations to be able to adequately care for their parents at home. For some, this resulted in financial insecurity warranting the need to access financial supports offered by the government which in some cases was accompanied by stigma. Financial concerns also arose after the death of a parent. These findings are discussed in more detail below.

The participants in Hossain and Khan’s (2019) study, made several substantial changes to their lives to accommodate care for their parents with dementia. A few of the participants started working less hours, others switched jobs, and some stopped working altogether and relied on government support for caregivers (Hossain & Khan, 2019). Similarly, some participants in Hossain’s (2021) study started working less hours, whereas others quit their jobs completely, or switched jobs to better accommodate around the clock care which had to be managed alongside household tasks. Participants shared how difficult it was to balance working while also being a fulltime caregiver, and while making changes to one’s employment allowed more time for caretaking duties, it also made caretakers’ lives challenging in other ways including financially (Hossain, 2021). Likewise, many of the adult-child caregivers in the study by Krishnamurthi et al. (2022) also had to let go of their employment because the home caretaking role required a large portion of their time on a day-to-day basis. Along similar lines, for some participants in the study by Herat-Gunaratne et al. (2020), the felt sense of duty to provide care at home until the end of one's parent's life was highly prioritized over other areas of life, including jobs which some caregivers had let go of.

Caretakers in Islam and Akter's (2021) study shared that they needed to be aware of the movements and actions of their family member with dementia throughout the day to ensure their safety, for example making sure they did not leave the home alone and get lost. Similarly, the caregivers in the study by McCleary et al. (2013) made adjustments to support the person with dementia and to help keep them safe both before and after diagnosis. This included putting reminder signs to turn cooking appliances off and generally being more watchful when the person with dementia was engaging in tasks that could become dangerous (McCleary et al., 2013). The impact that this had on the lives of the caregivers was not mentioned in the studies by Islam and Akter (2021) and McCleary et al. (2013).

One could surmise, however, that the need to constantly supervise the family member with dementia required significant adjustments in the caregivers' day to day lives such as changes to one's employment. Like the caregivers in the aforementioned studies, it is possible that some of the working participants in the studies by Islam and Akter (2021) and McCleary et al. (2013) either reduced their hours of work to better accommodate supervision and care, became unemployed, or had to make changes to their work schedules or environments.

Due to having to stop working or reducing hours to accommodate care, some of the caretakers in Hossain's (2021) study relied completely on government assistance which made them feel financially restricted in terms of what they could do in their lives as well as what they could provide to other family members such as their children. For other caregivers, despite needing financial support during the caregiving journey, seeking it from the government was accompanied with a fear of judgment from the South Asian community (Jutlla, 2015). This was the only study analyzed in this review in which stigma in the South Asian community related to government assistance was mentioned. Learning more about where this reluctance might be rooted would be supportive for mental health professionals working with individuals who find themselves in this situation. Financial issues also came up in the study by Hossain et al. (2022) in which the researchers' focus was to learn about the lived experiences of South Asian caregivers from the start of dementia symptoms until the death of the family member. In that study, many of the parents with dementia had expressed to their adult child caretakers that upon death, they wanted their bodies to be buried or ashes to be scattered in the countries they had been born in. Having to travel and arrange for the body or ashes to be taken to South Asia placed a financial burden on the adult children (Hossain et al., 2022).

It is important to note that not all participants faced financial hardship after becoming a caregiver to a parent with dementia. The level of financial burden varied from one participant to another, and there were other participants who felt financially secure throughout their caregiving journeys (Hossain, 2021). The authors did not delve into the factors that could explain this difference in perceived financial security; however, it would have been interesting to learn more so that the reader could gain greater insight into the varying finance related experiences of South Asian caretakers to parents of dementia.

Impacts to Social Life

In four of the eleven studies examined for this capstone, the topic of a diminished social life after moving into the caregiving role emerged. South Asian adult child carers in the study by Nielsen et al. (2021) noticed that their social lives reduced as they found it hard to get much time to spend outside of the home, and those who used to be part of their social circles struggled to understand their experiences and became distant. Growing distant from one's social circles relates to what was discussed earlier in this capstone about caregivers feeling lonely and disconnected from the South Asian community because others did not understand dementia and everything that being a caregiver entailed. The adult-child participants in Jutlla and Arblaster's (2023) study also experienced social isolation as a result of having to spend most of their time caring for their parent with dementia at home. Likewise, due to the role of carer being a dominant and time-consuming part of the carers' lives, participants in the study by Krishnamurthi et al. (2022) had to alter or minimize the time they could give to other areas, including their social lives which they had little to no time for. It would make sense if participants in the studies by Jutlla and Arblaster (2023) and Krishnamurthi et al. (2022) also experienced a loss of social support like caregivers in the study by Nielsen et al. (2021).

Impacts on Relationships

The topic of adult-child relationship issues as a result of becoming a caregiver came up in a few of the studies. This included worries about how relationships could be affected by the caregiving role, and actual lived experiences of how it negatively impacted romantic relationships. Conflict within familial relationships in relation to caregiving was also found to occur. These findings are expanded upon below.

Some of the male adult-child caregivers worried that their spouses especially new spouses who had moved into the home with them and their parent with dementia may feel burdened (Hossain, 2021). There were also participants concerned about how the caregiving role was having a negative effect on the relationship with their partner including not having enough time to nurture the relationship (Hossain, 2021). Clearly, feelings of worry on the part of the caregivers were prevalent; they wanted to care for their parent at home, and at the same time, worried about how this would impact their partner individually and the relationship as a whole. Indeed, there were some spouses of caretakers who were not happy with their partner’s role in their parent’s life and all that it entailed, and some participants shared that their romantic relationships had gotten to a point where they feared they could end (Hossain, 2021). However, despite the ways in which the caretaking role negatively affected romantic partnerships, the male adult-child caretakers in Hossain’s (2021) study continued to prioritize providing the best possible care to their parents. One caregiver, due to safety concerns for his mother, made it so that she was sharing a room with him and his spouse to allow for optimal supervision (Hossain, 2021). Similarly, the adult children in the study by Herat-Gunaratne et al. (2020) also highly prioritized providing care to their parent with dementia until the end of the parent’s life; this sense of duty resulted in the ending of romantic relationships for some participants.

Becoming a caregiver to a parent with dementia also came with challenges in navigating relationships with family members. Since many participants did not have awareness of dementia prior to witnessing symptoms in their parents due to an overall lack of awareness with South Asian communities, they had to try and explain it to relatives who did not always understand (Hossain & Khan, 2019). Participants found this especially difficult when trying to educate family members about the condition who did not believe anything was wrong with the parents while adjusting to a new way of life as caregivers (Hossain & Khan, 2019). Caregivers were also found to struggle with sibling relationships. Those who switched off providing care with other siblings sometimes experienced family conflict, such as when one sibling did not agree with how another was caring for the parent or when one sibling became resentful about taking on more care than the others (Nielsen et al., 2021).

Positives of Being a Primary Caregiver

As discussed previously in this review, South Asian adult-child carers to parents with dementia face many struggles, especially those who handle care with minimal support from others. However, not all adult children experienced being the primary caregiver of choice to be completely burdensome. Some participants in the study by Nielsen et al. (2021) seemed to take pride in caring for a parent with dementia. There were also participants in the study by Herat-Gunaratne et al. (2020) who viewed the journey of being a caregiver from a positive perspective; those adult-children were able to find an appreciation for the quality time it allowed them to share with their parent and felt that their role was meaningful and purposeful. It is important for counsellors to know that while the role of providing care to a parent with dementia can be difficult, it can also be rewarding and benefit the mental well-being of South Asian adult-child caregivers. It could be something that counsellors might encourage clients to draw upon for a sense of purpose and strength during difficult times.

Other factors such as being more educated and having and a greater awareness of the available resources made the caregiving experience easier to navigate for some of the caregivers which resulted in a more positive experience overall compared to those who lacked awareness and had lower levels of education. Nielsen et al. (2021) found that adult children who had higher education knew of supportive resources and tended to utilize them more than those with lower levels of education. Similarly, Jutlla (2015) found that adult children who had immigrated from India to South Africa, and then to the United Kingdom, were better able to advocate for and gain access to external support services due in part to being more educated. One participant shared that in her experience, the Sikh, Punjabi community in

East Africa tend to have higher education levels and generally work towards improving their overall quality of life compared to Punjabi, Sikh individuals who immigrate straight to England from rural parts of Punjab, India (Jutlla, 2015). This participant described her role as primary caregiver for her father-in-law as positive overall (Jutlla, 2015).

Unlike the caregivers in many other studies, however, the caregiver in Jutlla's (2015) study did not have to balance her caregiving duties with a job and utilized home care services seemingly without any hesitations as she viewed them as being necessary. This was not a viewpoint expressed by other caregivers in this study or any of the other works examined. Other studies found that South Asian adult-child caregivers either minimally utilized home care services if at all, or were not always satisfied when they did which led to decreased usage (Herat-Gunaratne et al., 2020; Hossain, 2021; Hossain & Khan, 2019; Hossain, 2021; James et al., 2023; Krishnamurthi et al., 2022; Nielsen et al., 2021). This was often due to language barriers and care support staff having a lack of awareness of culturally and religiously appropriate care practices. No such barriers were mentioned in the Jutlla (2015) study participant's experience of care support which is curious. Perhaps her father-in-law did not adhere as strongly to South Asian cultural norms and/or religious practices. Whatever the case may be, it highlights the fact that while there can be similarities amongst South Asian caregiving experiences, it is important not to generalize as there are outliers whose experiences may be different.

Support from other Family Members and Extended Networks

There were mixed findings in the studies in terms of how involved individuals outside of the primary adult-child caregiver were in the care of the person with dementia. The carers in the study by Nielsen et al. (2021) did not feel that relatives outside of the immediate family or those within the same ethnic group were helpful to them. This is similar to the finding in Krishnamurthi et al. (2022), where most participants handled care tasks on their own with minimal support from other relatives. However, it contrasts with the results of the study by Herat-Gunaratne et al. (2020) in which adult-child caregivers found their extended networks to be greatly supportive.

The adult child carers in the study by Nielsen et al. (2021) switched off caring for their parent with dementia with other family members who were usually their siblings. This allowed the primary caregivers to get some respite from the caregiving duties and give time to other areas of their lives including their jobs, day-to-day house tasks, children, romantic relationships, and their social lives (Nielsen et al., 2021). In some cases, the parent with dementia would consistently live in one home while the children switched off caring for them there every few days, weeks, or months. In other cases, the parent was moved to the adult child's home who would be caring for them at the time (Nielsen et al., 2021). The results indicate that this system tended to work well for many of the South Asian caregivers in the study; however, it did not come without its challenges as discussed in the section about impacts to relationships.

Some of the female adult-child caretakers in Hossain's (2021) study felt a lack of care support from their male partners. They attributed this to Bangladeshi cultural norms of men not valuing caretaking in the same way that women do and therefore they did not expect men to be helpful when the need for caretaking support arose (Hossain, 2021). Their experiences of gender norms are valid, especially since around three quarters of the study participants were females (Hossain, 2021). At the same time, it should be noted that this perspective is contrary to the caretaking experiences shared by all three male adult-child caretakers in the same study which indicated that caring for their parents was highly important to them. There was also no mention of their female spouses being involved in the care. Moreover, not all female partners of male adult-child caregivers were understanding when it came to sons providing care to their parents (Hossain, 2021). Could it be possible that other factors outside of or in addition to gender could be influencing the tendency to take on a caretaking role, such as whether the parent is one's own parent or a parent-in law, upbringing, or personality?

Summary

In this chapter, several emerging themes within the literature on the topic of South Asian adult-child caregiving experiences to parents with dementia were examined amongst eleven peer-reviewed studies that took place within different Western nations. One of the themes was the different types of systemic barriers encountered by South Asian caregivers. Following this was a discussion of how most caregivers had little to no knowledge about dementia prior to their experiences with their parents and how this affected their caregiving journeys. After this, filial duty and its influence on providing care was discussed. Then, there was an exploration of the different areas of life affected by the caregiving role including mental health, physical health, social life, career and finances, and relationships. Additionally, there was a discussion on the positive aspects of caregiving. Finally, caregiver experiences with support from family and friends were examined. The next chapter will delve deeper into some of the themes and subthemes that emerged in this chapter as they relate to and inform the field of counselling psychology. Findings will be explored more extensively and there will be discussion as well as proposed application on how the knowledge uncovered from this review can inform future practices of mental health professionals working with South Asian adult children caring for parents with dementia in Western nations.

Chapter 3: Discussion and Application

This section of the capstone will consist of a deeper discussion about some of the findings that surfaced from the analyzed studies, including insights that emerged and limitations that were noted in the overall research on the topic of the lived experiences of South Asian adult-children caring for parents with dementia in Western nations. The discussion of systemic barriers related to the healthcare system and language will be expanded upon. There will also be a focus on the idea of migration-related social location as a greater barrier to care support than culture. Additionally, there will be explorations of changes to self-identity and grief, the experiences of first-generation South Asians with filial duty, assumptions about South Asian culture and familial support, the influence of gender norms on caregiving, stigma associated with dementia, invalidation of mental health struggles, unawareness of dementia, and loneliness. To follow will be a proposed idea for a support group designed specifically for South Asian adult-children caring for parents with dementia. After this will be a discussion of ethical considerations that must be kept in mind when working with this population. I will then reflect upon how working on this capstone project has expanded my knowledge and given me a greater appreciation of what it means to be caregiver to a parent with dementia. The capstone will conclude with an overall summary of the insights gained from the literature.

Healthcare System Barriers to Diagnosis and Support

Family physicians not taking dementia symptoms seriously was a recurring theme throughout various studies (Hossain & Khan, 2019; Islam & Akter, 2021; Krishnamurthi et al., 2022). These experiences seemed to either reinforce caregivers' existing beliefs that dementia was a normal part of ageing or misinformed them that this was the case. This resulted in late diagnosis due to a delay in individuals with dementia being connected with specialists for assessment. Participants across several studies expressed that doctors did not suggest any resources outside of medication once dementia was diagnosed (Islam and Akter, 2021; Jutlla, 2015; Jutlla & Arblaster, 2023). The caregivers could have benefited from learning about dementia related supports available in the community, such as financial support, home care support, transportation support, day centres, support groups and more. It would be important for mental health professionals to know about such resources for the times that they encounter a client who is struggling with their role as caretaker for a family member with dementia. Mental health professionals could help ease the mental load by suggesting the resources and/or possibly helping clients advocate for greater support within the healthcare system, such as helping them get their family members referred to dementia specialists.

Language Barriers

Language barriers in relation to accessing external supports seemed to be an issue for some participants who had immigrated to Western nations in adulthood (Hossain, 2021; Islam & Akter, 2021; Jutlla, 2015). This would be important for counsellors to be mindful of when working with clients who have immigrated later in life and are not as proficient in English as those who may have immigrated earlier in life. Counsellors should be careful, however, not to make assumptions about the English proficiency of a client based on their immigration history as this would vary from person to person. For instance, a South Asian person who immigrated in mid-age may be highly proficient in English depending on a variety of factors including their level of education and where they lived before. As found in Jutlla's (2015) study, South Asian adult-child caregivers who had either been born in the United Kingdom, immigrated there as children, or had first immigrated from South Asia to Africa and then to the United Kingdom tended to feel more confident in their ability to advocate for their family member with dementia. This was partly due to not experiencing language barriers when seeking and accessing support services. In contrast, those who had immigrated to the United Kingdom directly from villages in India in adulthood did experience language barriers which made it harder to access the needed support services (Jutlla, 2015).

The Idea of Migration-Related Social Location as a Greater Barrier to Care Support than Culture

Based on the results of her study, Jutlla (2015) contends that it is not so much the cultural differences between South Asians and the dominant White British that seem to explain the differences that account for access to and utilization of formal support resources, but rather the immigration experiences and the resulting social locations of South Asians residing in the United Kingdom. This offers a very different perspective from the other studies analyzed in this capstone in which the influence of immigration histories on caregiving experiences are minimally discussed. Jutlla's (2015) study therefore brings light to an important consideration that needs to be made when counsellors are working with South Asian caregivers to parents with dementia. It would be important to have insight into how the immigration experiences (or lack thereof) can present different challenges and benefits for different caregivers within the larger South Asian community.

Changes to Self-identity and Grief

Adult-child caregivers reported a shift from seeing their parent as someone they could go to for guidance and wisdom prior to the dementia symptoms worsening, to losing this after the condition progressed (Hossain, 2021). Participants shared that they experienced a role reversal when this shift occurred, where they started to feel like they were needing to parent their own parents (Hossain and Khan, 2019) with some saying that it was harder than caring for a newborn (Hossain, 2021). It was implied that the adult children felt grief as they went through this role transition as they shared that the parent they used to know no longer existed (Hossain, 2021); however, authors did not explore the grief experience. It is possible that the participants themselves chose not to delve into further detail, or perhaps the authors chose not to focus on this piece. Regardless, these findings are highly relevant to mental health practitioners who could use this insight to inform the approaches and techniques they use with clients going through such role changes and grief.

Assumptions about South Asian Culture and Familial Support

James et al. (2023) noted that non-South Asian dementia specialists held the general assumption that South Asian families had large supportive familial networks and therefore would not benefit from formal assistance; however, there were some South Asian caregivers who brought awareness to the fact that this assumption could unintendedly exclude and deprive caregivers of much needed support. One participant in the study by James et al. (2023) expressed concern about adding burden to the lives of other family members by asking for help; she felt they were busy and had other important commitments which she did not want to disrupt. So, although from an outsider perspective, it may look like the primary caregiver has many other people in the family who could help ease the caregiving strain, those individuals may neither wish nor be able to be involved. If professionals in positions of power such as counsellors do not feel that South Asian families need external supports, it could decrease the chances of greater resources specific to South Asians being created.

James et al. (2023) also highlight the need for external care services within South Asian communities. One South Asian adult-child caregiver in this study who had a Muslim Bangladeshi background shared that her mother did not feel comfortable with members of the family helping her with tasks related to toileting and bathing (James et al., 2023). In this case, the caregiver benefited from having a support worker to take care of these tasks because it was her mother's preference, which the caregiver shared was influenced by South Asian culture (James et al., 2023). This is the only study examined in this capstone in which South Asian persons with dementia preferred someone outside of their family to provide care related to personal hygiene tasks, especially when the gender of the family caregiver was the same. In other studies, such as the one conducted by Herat-Gunaratne et al. (2020), the persons with dementia seemed to prefer that family members do these tasks except when the gender was not a match, for example a son providing hygiene care to his mother (Herat-Gunaratne et al., 2020).

The Influence of Gender Norms on Caregiving

The implications of Bangladeshi women taking on the majority of caregiving duties with minimal support from men (Hossain, 2021) could be worth exploring further. This is because the beliefs or assumptions that female caretakers have could influence their tendency or likelihood of reaching out to male family members for support. According to what the female participants shared, it would make sense if a Bangladeshi daughter who is caring for a parent with dementia feels overwhelmed but chooses not to reach out to males in her family because she assumes that they will not be helpful when this may not be the case. It could be a missed opportunity to ease the caretaking burden and to replace feelings of resentment with gratitude or appreciation which could improve relationships, the caretaker's mental health, and ultimately the caretaker's overall quality of life. Female participants also expressed that being in the role of a caretaker was especially difficult for them due to also having to take on the majority of the household duties (Hossain, 2021). This was not further expanded upon, but it would have been interesting to learn more about the experiences of the female Bangladeshi caretakers and how they felt their experiences differed from male Bangladeshi caretakers in terms of household task distribution.

Stigma Associated with Dementia

A theme that came up in the literature review was that of dementia related stigma experienced by South Asian adult-child caregivers. It was found that due to mental unwellness being stigmatized within South Asian communities, caregivers in some studies opted to keep the dementia hidden from relatives, as well as from South Asian friends and neighbors (Hossain et al., 2022; Islam & Akter, 2021). This finding is of great significance and relevance to mental health professionals as stigma would likely be associated with difficult feelings that caregivers could benefit from processing. Feeling like one must keep their parent's condition a secret, especially when it consumes a large part of one's life, would be incredibly difficult emotionally. Doing so would presumably also close caregivers off from reaching out to others in their South Asian communities for support, whether that be emotional support or otherwise. Moreover, keeping this to themselves would likely make them feel more isolated in their experiences of caregiving. It might be good for counsellors, especially those working in areas with larger South Asian populations, to create support groups for South Asian caregivers so that there is a space for them to share their experiences with others in case this is something that they have trouble talking about with their own extended family and friends.

Lacking in the Literature: First Generation South Asian Caregivers and Filial Duty

For the majority of adult-child caregivers in the studies included in the literature review, a sense of filial duty was a strong motivating factor to become an at-home caregiver for a parent with dementia (Herat-Gunaratne et al., 2020; Hossain & Khan, 2019; Hossain et al., 2022; James et al., 2023; Krishnamurthi et al., 2022; Nielsen et al., 2021). For some, caring for parents, parents-in-law, or grandparents with dementia served as a way to get the blessings of their elders and engage in their filial duty (Hossain et al., 2022). From a therapeutic perspective, this may act as a protective factor for caregiver mental health (Sampogna et al., 2024). However, some caregivers, particularly those who were born and raised in the United Kingdom, expressed that the concept of filial duty in South Asian culture was not in line with the culture in the Western world (Herat-Gunaratne et al., 2020). Although this was not further explored, learning more about how bicultural first generation South Asian adult children living in Western nations navigate the polarities between two cultures while in the caring role would have provided some valuable insight on the unique experiences of these individuals. Perhaps future studies could focus on this specific population.

Lacking in the Literature: Influence of Parent-Child Relationship on Caregiving

Related to filial duty, another area that was untouched in the literature examined for this capstone was how the adult-child's experience as a caregiver is affected by the relationship they have with their parent. The strong expectation present in South Asian culture for adult children to provide care to their parents in old age does not take into account the type of relationship that exists between the parents and children. The concept of filial duty seems to imply that one should give back to their parent in the form of caring for them in old age regardless of any relationship related factors. The expectation exists irrespective of how the parent has treated the adult child, and how the adult child feels about taking on such a significant life-altering role seems to be disregarded. One can imagine how feeling obligated or pressured by other relatives to provide care for a parent who one has resentment towards could bring about difficult emotional and psychological experiences. Although none of the participants in the studies examined in this capstone spoke about the type of relationship they had with their parent, some did state that they did not view being a caregiver as a choice due to the filial duty expectation and that it would be “taboo” not to take on the caregiving role (Nielsen et al., 2021).

Alternatively, having had a great relationship with a parent before and after dementia and feeling a sense of familial duty stemming from cultural expectations could be empowering for a South Asian adult-child who has found themselves in the caregiver role. By caring for their parent, they may experience a sense of fulfilment in giving back the care they received while growing up. However, there will be adult children within South Asian communities who do not feel fondly toward their parent and would rather not be the ones to provide care, but not doing so would fall outside of cultural norms and potentially come with guilt and scrutiny from others within the community. The influence of relationships between South Asian adult children and their parents with dementia on caregiving experiences in relation to filial duty is an area that remains to be explored in the literature. Counsellors knowing about how cultural factors such as the expectation or duty to care can impact different individuals would help South Asian adult-child caregiver clients to feel better understood and validated in their experiences.

Invalidation, Unawareness, and Loneliness

Caregivers who were born in Western nations or who immigrated in childhood felt invalidated in their difficulties by those who had immigrated in adulthood (Jutlla, 2015). They were expected to be just as resilient as those who immigrated later in life, and when that was not the case, they did not feel understood or supported which led to feelings of loneliness, depressive symptoms, and even thoughts of suicide (Jutlla, 2015). Caregivers also experienced loneliness within South Asian communities due to lack of dementia knowledge and resource awareness (Jutlla & Arblaster, 2023). They found themselves wishing medical professionals would have educated them on what dementia was and how to best provide care (Hossain et al., 2022). One can imagine how difficult it would be to learn that one's parent has dementia but not knowing what it is, getting minimal information about it from medical professionals, and not being able to find support in one's family and friends because they are unaware of the disease, all while adjusting to the life of caregiver. Loneliness was also experienced when caregivers witnessed the health of their parents decline until their deaths (Hossain, 2021).

It is clear from these experiences of loneliness, invalidation, and unawareness, that South Asian adult-child caregivers could benefit from having a safe space to connect with other South Asians who are also going through similar struggles. One daughter shared that she attended a once-a-month support group for family caregivers which was the only time she would get away from her caregiving duties (Jutlla, 2015). The authors did not provide any details about the support group and the impact it may have had on the caregiver's life, but this would have been beneficial to know.

Applied Practice

Based on the findings of this capstone, I propose a support group for adult children caring for parents with dementia in South Asian communities in Western nations**.** Below, I will discuss the rationale for creating the group, objectives of the group, inclusion and exclusion criteria, logistics, and a description of the group. There will also be a discussion of ethical considerations. An outline for the proposed support group can be found in the Appendix.

Rationale and Objectives

As demonstrated in the literature analyzed in this capstone, South Asian adult children caring for parents with dementia have unique struggles related to their role and social locations that warrant the need for mental health support. This includes stigma surrounding dementia in the South Asian community, preventing caregivers from talking about their struggles and reaching out for support. Also uncovered were the feelings of loneliness that can result not only from stigma but from trying to navigate adjusting to the life of a caregiver, while learning about dementia and teaching family members about it who may not always understand. Various systemic issues are also encountered by South Asian adult children which can be difficult to navigate. Moreover, adult-child caregivers grieve throughout the journey of caregiving. They grieve the relationship they once had with the parent who has dementia, they grieve the ways in which their lives and self-identity change in the process, and they grieve as they watch their parent's health deteriorate until end of life. Additionally, South Asian caregivers struggle with the expectations that come from their parents, extended family, and South Asian cultural norms with which they do not always align.

All these findings strongly suggest that South Asian adult-child caregivers to parents with dementia could greatly benefit from the therapeutic and social support that would be afforded by taking part in a therapy group designed specifically for this population. One objective of the group is to give these individuals a safe space to share their challenges related to the caregiving role, especially for those who do not feel that they can talk about these struggles with other family members or friends. Another objective is to provide them with different tools and techniques to utilize throughout the caregiving journey to support their mental well-being.

Inclusion and Exclusion Criteria

It is important to me that the support group be specifically for adult children only and not all South Asian family caregivers. Grouping South Asian caregivers together regardless of their relationship to the person with dementia would make the group too broad and not as focused as I would like it to be. The experiences of adult-children would differ from those who have a different relationship to the person with dementia. Spousal caregivers, for example may not have the same expectation upon them to provide care at home until the end of life that adult children would, due to the cultural belief of filial duty. They would also not experience role reversal like adult children might. Therefore, only those who are the South Asian adult children to parents with dementia would be included. All ages would be welcomed.

Group Logistics

The group would take place on a biweekly basis for a total of 10 weeks, and each session would be 1.5 hours long. It would be virtual to allow caregivers to remain home so that they do not have to worry about being too far away from the parent. A South Asian therapist would ideally facilitate the group to allow for optimal understanding of caregiving issues and struggles related to South Asian cultures. As discussed in the literature review, there are several subcultures within South Asian culture, and the experiences within each may differ in some ways from another. Also discussed were the language barriers experienced by some South Asian adult-child caregivers depending on their level of English proficiency. Therefore, different versions of this support group would exist, and each would be facilitated by South Asian counsellors who belong to different South Asian subcultures and can speak other languages outside of English such as Punjabi, Hindi, Bengali, and Gujarati. If the counsellors themselves cannot speak the specific language needed for the group members, a translator who can, would be present.

Group Description

The group would be person-centered and psychoeducational in nature. It would also incorporate some mindfulness activities and art therapy. Most sessions would include a grounding activity to help participants feel more present and relaxed as they engage in the group. They would also include discussions based on the topic of the week, as well as activities that would either be done as a group, or individually with the option to share with the other participants. Psychoeducation would be incorporated throughout the sessions. The first week would be the introduction session to the group in which informed consent forms would be reviewed including limits to confidentiality. The intentions of the group would be shared, the weekly outlines would be reviewed, and group expectations would be co-created. There would also be a discussion on when participants first noticed dementia symptoms in their parent, how long they have been a caregiver for, and what their initial thoughts were upon learning that their parent had dementia. Weeks 2-9 would cover the following topics: systemic barriers, stigma within South Asian communities, loneliness and social support, conflict with other family members in relation to caregiving, filial duty and its impact, the relationship with one's parent, grief and loss, self-care, and the power of gratitude practices. The final session would invite participants to share the parts of the group that have been the most impactful for them, as well as if there were other topics they would have liked to discuss. There would also be a collaborative group closing activity**.** More details can be found in the Appendix.

Ethical Considerations

There are several key ethical considerations that counsellors ought to keep in mind when working with South Asian clients who are caregivers to parents with dementia. One is ethical standard I.16 under Principle I: Respect for the Dignity of Persons and Peoples in the fourth edition of the *Canadian Code of Ethics for Psychologists* (Canadian Psychological Association, 2017), which states that counsellors must ensure that they get informed consent from clients. This includes making clients fully aware of what their participation would entail and informing them that they always have autonomy. This would apply to one-on-one counselling sessions as well as group therapy. Another is standard II.10 under *Principle II: Responsible Caring* (Canadian Psychological Association, 2017), which holds that counsellors should be aware of their lived experiences, social locations, intersectionality, and beliefs and how they could influence their work with clients. It is important for counsellors to engage in self-reflection about this so that they can minimize harm to clients and be of the greatest service to them. It is also important to adhere to Article B9. *Respecting Inclusivity, Diversity, Difference and Intersectionality* in the Canadian Counselling and Psychotherapy Association Code of Ethics (2020) which reminds counsellors that there can be differences not only between different groups, for example two different South Asian subcultures, but also within groups. For example, the experiences of one Hindu, Bangladeshi adult-child caregiver will not necessarily be the same or similar to that of another Hindu, Bangladeshi adult-child caregiver.

Reflections on Personal Learning

I have gained a greater level of insight into the lived experiences of South Asian adult children caring for parents with dementia than I had when I first began working on this capstone. I went into it with the mindset that the role is mainly taken on by female adult children because of what I had observed in my extended family, but the findings of the studies I analyzed indicated that this might not necessarily be the case**.** In many studies, there were similar ratios of male to female caregivers which surprised me. It affirmed one of the intentions I had in chapter 1 to mitigate my bias, which was ensuring that I was not specifically looking for studies with only female adult-child caregivers. I understood that doing so would not have provided an accurate representation of the caregiving role for all adult children of South Asian ethnic origins.

The capstone also helped me to broaden my perspectives on the hardships that adult-child caregivers can face when accommodating care for a parent. For example, it had never occurred to me that filial duty could play such a strong part in the motivation to care for a parent at home, that romantic relationships could end because of it being prioritized. Now that I think back to what I have observed in South Asian communities as a person who is a part of them, I can see how a marriage could end if the spouse of an adult-child caregiver were unsupportive of the caregiving role. This is because I know how strong the duty to care for parents or grandparents can be within South Asian cultures as I have felt it myself. There have been many times where I have prioritized spending time with and caring for my grandparents above all else.

The findings about structural barriers, specifically the ones within the medical system, were also very eye-opening for me. Of particular note was the finding in multiple studies where dementia diagnosis was delayed largely due in part to family physicians not taking symptoms seriously and telling patients that dementia is a normal part of ageing. When I had dementia concerns about my grandfather, I accompanied him to his appointment. When I mentioned my concerns about the behaviour changes I was noticing and asked if they could be dementia related, the doctor told me dementia was normal due to the age of my grandfather. As I have learned through my research for this capstone, that could not be further from the truth.

Overall, I have gained great knowledge as a result of embarking on this capstone project. I am grateful to have had the opportunity to delve deeply into an area that has been an interest of mine for several years now. I cannot think of a better way to conclude my educational journey at City University, my final chapter before I begin my work as a clinical counsellor. I am hopeful that the findings uncovered will be supportive for others including South Asian adult-child caregivers to parents with dementia living in Western nations, and any mental health professionals who may find themselves working with this population.

Conclusion

This capstone has found that South Asian adult-child carers to parents with dementia in Western nations face many struggles including confusion and loneliness as they attempt to learn about dementia while also educating the largely unaware South Asian community about it. They face systemic barriers in terms of limited access to resources that are in line with culture, language, and religion. They also face hurdles within medical systems e.g., symptoms not being taken seriously by doctors, delays in being connected with specialists, and delays in or lack of diagnosis. Feelings of helplessness arise when medical professionals do not inform caregivers about what they can do to help their parent outside of making sure they take their medications. Moreover, many South Asian adult children feel a filial duty or obligation to care for their parents at home, and many parents seem to have this expectation of their children too which is deeply embedded into South Asian cultural norms.

While the concept of filial duty is supportive for some adult children, others may feel burdened by it. As discussed in this capstone, several of the studies included participants who felt this way. For many, filial duty expectations within South Asian culture prevented them from getting the extra support they needed, not only from formal support services like home care workers or day centres, but in some cases, it also prevented them from reaching out to other family members. Feeling that they could not reach out and had to handle the majority (if not all) of the care on their own had a detrimental impact on the caregivers' lives. As discussed, the role was so time consuming that it required adult-child caregivers to alter their lives to fit around it. This often required sacrifices like reducing or letting go of employment which negatively affected finances. It also resulted in no longer having time for socializing, less time to put toward maintaining relationships (romantic and otherwise), and making changes to accommodate care that would negatively impact relationships e.g., parent sleeping in the same room as the adult-child and their spouse.

In the end, caregivers were left with little to no time for themselves and their mental health was greatly diminished which is highly relevant for mental health professionals**.** This is especially true, because from some of the participants' responses, it was clear that talking about their mental health struggles with their families and others within the South Asian community was not something they felt they could do. For some it was due to gender norms e.g., males not feeling like they could talk to other males about emotions. For others it was about feeling pressure from others within the South Asian community to be able to cope well without any issues. There were also participants who outright said that they wished there had been some kind of support group for them, and one who shared that she did manage to attend one and that it was helpful. It is clear that South Asian adult children caring for parents with dementia at home in Western nations could benefit from having extra support from mental health professionals as they navigate the caregiving journey. In the applied practices section, I propose a counselling group tailored specifically to South Asian adult-child caregivers of parents with dementia that could be implemented by counsellors. My hope is that more research will be done on this specific population so that there may be greater awareness of their unique experiences and needs.

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Appendix

Support Group for South Asian Adult-child Caregivers to Parents with Dementia: Outline of Sessions

Week 1: Introductions

Self-introductions

- Icebreaker Question: What is your energy level today?

Reviewing Informed Consent Forms including limits to confidentiality, and answering questions

Explanation of the intentions of the group

Reviewing the outline for Weeks 1-10 as a group

Group Discussion

- When did you first notice the dementia symptoms and for how long have you been a caregiver?
- What were your initial thoughts upon learning about the dementia?

Group Activity

- Develop expectations for the group

Grounding Activity

- Guided Mediation + Psychoeducation behind it

Week 2: Systemic Barriers

Group Discussion

- What are some barriers you have all faced as caregivers?
- How have these barriers affected you and your family?
- How can we combat them?

Group Activity

- In small groups: “Wearing your strengths” activity

- Taking turns, each person will tell a two- or three-minute story of a difficult time in their life and how they overcame it. While they are doing this, the three listeners in the groups will be writing key words or phrases on sticky notes:
- Person 1/Blue Sticky Notes: What were the personal qualities and strengths of the person?
- Person 2/Pink Sticky Notes: What was difficult about his/her situation?
- Person 3/Yellow Stick Notes: What feelings is the storyteller expressing?
- Person 4 (no sticky notes): Storyteller
- Once the storyteller finishes sharing, the 3 listeners will stick their sticky notes onto the story teller's body. Then, roles will be switched until everyone gets a chance to be the storyteller.

Grounding Activity

- Body Scan + psychoeducation behind it

Week 3: Stigma within South Asian Communities

Grounding Activity

- Belly Breathing + psychoeducation behind it

Group Discussion

- Have you experienced or witnessed stigma around dementia in your social circles? If yes, how has it shown up?
- How has it affected your experience as a caregiver?

Group Activity

- Brainstorming session: What can we do to decrease this stigma in our South Asian communities? And what might be some benefits of doing so?

Week 4: Loneliness and Social Support

Grounding Activity

- Five Senses Activity + psychoeducation behind it

Group Discussion

- What are some experiences of loneliness that you have had as a caregiver?

Psychoeducation

- The importance of social support and how we can foster it

Group Activity

- Brainstorming and compiling a list of additional ways we can broaden our social support circles

Week 5: Conflict with Other Family Members in Relation to Caregiving

Grounding Activity

- Guided Meditation

Group Discussion

- Do you or your other family members ever have disagreements related to caring for your parent?
- If so, how have you handled these in the past and what has been the outcome? And what might be some alternative approaches?
- If not, how do you think you have managed to avoid it?

Psychoeducation

- How to Cope with Stress

Week 6: Filial Duty and its Impact

Grounding Activity

- Belly Breathing

Group Discussion

- What are your thoughts about filial duty in relation to your own experiences?

Group Activity

- Brainstorming session: Pros and Cons - Working on a digital table as a group with the positive elements of filial piety on the left side and the negative elements of it on the right side.

Week 7: Relationship to your Parent

Grounding Activity

- Five Senses Activity

Group Discussion

- Has the way you relate to your parent changed since the symptoms emerged? If yes, how so?
- What are some good things that have come out of this?
- What**,** if anything**,** do you miss about how things were between you and your parent before the dementia?

Group Activity

- Journaling for 10 minutes straight without worrying about grammar or punctuation in response to this journal prompt: “What thoughts and feelings has today’s discussion topic brought up for you?”
- Opportunity for sharing

Week 8: Grief and Loss

Grounding Activity

- Body Scan

Psychoeducation

- Anticipatory Grief

Group Activity

- Journaling for 10 minutes straight without worrying about grammar or punctuation in response to journal prompt: “One of the ways I have experienced anticipatory grief is…”

- Opportunity for sharing

Psychoeducation

- Coping Strategies for Anticipatory Grief

Group Activity

- Art therapy – painting (supplies will be mailed to everyone in advance)

Week 9: Self-Care for the Caregiver and the Power of Gratitude Practices

Grounding Activity

- Guided Meditation

Group Discussion

- What is self-care?
- What are some small ways we can incorporate self-care into our days while caregiving?

Psychoeducation

- The Power of Gratitude Practices

Group Activity

- Making a gratitude jar (jar + decorating materials will be mailed to everyone ahead of time)
- After decorating, think of one thing you are grateful for today. Write it down on a piece of paper along with the date, then fold it up and put it in the jar. Continue this practice daily either before going to sleep each night or in the mornings. On days you need a pick-me-up, pick some notes out of the jar to remind yourself of the times you felt gratitude.

Week 10: Closing

Grounding Activity

- Five Senses Activity

Group Discussion

- What have been the most impactful or helpful learnings or activities for you?

- What are some topics that you would have liked to discuss?

Group Closing Activity

- Art therapy: Creating a digital collage with words and pictures that depict highlights and learnings from the group
- The completed collage will be emailed to everyone
- Complete the Feedback Form