THE EXPERERIENCE OF BEREAVED SOUTH ASIAN FAMILY CAREGIVERS

THE EXPERERIENCE OF BEREAVED SOUTH ASIAN FAMILYCAREGIVERS OF ADULT FAMILY MEMBERS

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Lay Abstract

The South Asian community faces many challenges when receiving palliative care, including language barriers and health care providers (HCP) who do not understand the South Asian culture. However, little is known about the needs and experiences of South Asian family caregivers. In this study, South Asian caregivers of family members who recently died described their experience of being a family caregiver. Caregivers had a strong sense of duty to their family members and were against moving their family members into long-term care homes or hospices. Their understanding and views of HCPs' roles affected their experiences. Caregivers also had more appreciation for life and wanted to talk about their wishes for their own death with their family members. The findings of this study can help improve the delivery of palliative care for the South Asian community and can help HCPs better support their South Asian patients and families.

Abstract

The South Asian population faces several challenges when receiving palliative care, including language barriers, unawareness of resources, and poor cultural awareness among health care providers (HCP). However, little is known about the needs of South Asian family caregivers in Canada. The purpose of this study is to understand the experience of bereaved South Asian informal caregivers, who cared for a family member in their last year of life. An interpretive descriptive design was used.

Eleven participants were recruited by referral through a community hospice and a community health centre. Participants were South Asian informal caregivers and at least two months bereaved. Audio-recorded one-on-one interviews were conducted followed by a thematic analysis of the transcripts. Five themes were identified to describe the experience of bereaved South Asian informal caregivers: transforming perceptions of life and death, the influence of culture on the experience; the challenges of being a caregiver; coping with the challenges of care-giving; and getting support. Caregivers expressed feeling a sense of duty to their family members and were reluctant to utilize long-term care homes or hospices. The perceived hierarchy of HCP roles also affected their experience. In reflecting on their experiences, caregivers had a deeper appreciation for life and were more willing to talk about death and dying.

The experience of South Asian family caregivers is complex with several underlying cultural influences. This study has important implications in improving the delivery of culturally sensitive palliative care and developing supports that address the challenges experienced by caregivers in the South Asian community.

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CHAPTER 1

INTRODUCTION

South Asian Immigrants in Canada

Canada continues to attract many immigrants, with over 271,000 permanent residents accepted into Canada in 2016 (Government of Canada, 2016). As per the 2016 census, 22.3% of the total population is made up of visible minorities (Statistics Canada, 2017a). South Asians are the largest group of visible minorities in Canada, accounting for 25.1% of the total visible minority population and 5.6% of the total Canadian population (Statistics Canada, 2017a). The term "South Asian" refers to individuals who descend from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan or Sri Lanka (Statistics Canada, 2017b). As of 2015, India and Pakistan are among the top five countries from which immigrants arrive to Canada (Government of Canada, 2017).

It is reported that the population of visible minorities is largely scattered across the provinces of Alberta, British Columbia, Ontario and Quebec (Statistics Canada, 2016). However, the largest population of visible minorities resides in Ontario (Statistics Canada, 2016), where Toronto is home to 53.2% of the total Canadian South Asian population (Statistics Canada, 2016). Therefore, it is evident that health care services in Ontario and across Canada are accessed by a diverse population, of which a significant proportion is of South Asian descent. As such, it is important to consider cultural diversity when developing resources and building the Canadian healthcare system. Culture is defined as information, values and beliefs among members of a social group that shape attitudes and have significant meaning (Registered Nurses Association of

Ontario, 2007). It is influenced by many factors including, but not limited to, race, ethnicity, religion, life experience or socio-economic status (Registered Nurses Association of Ontario, 2007).

The Palliative Approach and Culturally Sensitive Care

The palliative approach focuses on maintaining quality of life by providing palliative services that will help improve or maintain quality life of both the patient and the family as they move forward through the illness trajectory (Bacon, 2012; Sawatzky et al., 2016). This can be achieved through symptom management, effective communication, appropriate end-of-life (EOL) care and bereavement support (see Appendix A for Glossary of Terms). The palliative approach begins at the point of diagnosis and continues into the stage of bereavement (Canadian Hospice Palliative Care Association, 2015; Sawatzky et al., 2016). The approach emphasizes a patient-centered and family-centered approach to care and reinforces the importance of moving beyond physical needs to address psychosocial and spiritual needs of the patient and family (Bacon, 2012; Sawatzky et al., 2016). There are several factors that influence the experience and delivery of care (Fowler & Hammer, 2013). Culture is one such factor that affects patients' and families' health care experience, particularly in the end-of-life (EOL). The Canadian Hospice and Palliative Care Association (CHPCA) has developed the Square of Care framework that reflects a wholistic palliative approach to care by addressing different aspects of care (see Appendix B) (CHPCA, 2013). This framework includes nine domains of care and common issues faced by patients and families (CHPCA, 2013). The "social" domain in particular encourages the acknowledgement of cultural values, beliefs and practices in the delivery of a palliative approach (CHPCA, 2013), thereby encouraging a wholistic approach to care.

Given the cultural diversity of the Canadian population and the increasing aging population, the need for culturally sensitive care within a palliative approach has increased (Fowler & Hammer, 2013). In order to meet this need, health care providers (HCP) often strive to achieve cultural competence. Cultural competence is defined as the ability to support cultural diversity by eliminating racially or ethnically fuelled discriminatory behaviours or attitudes (Registered Nurses' Association of Ontario, 2007). However, the term cultural competence implies an achievable, quantifiable and finite amount of knowledge about a certain culture that can be effectively demonstrated by a qualified HCP (Tervalon & Murray-Garcia, 1998). Cultural competence supports the inaccurate notion that culture is static with a fixed set of the same values, traits, and practices upheld by individuals of a shared culture (Kirmayer, 2012). In reality, culture is ever-changing and flexible, and its presentation varies between individuals, groups or communities (Kirmayer, 2012). Thus, the term cultural humility may be better suited to describe HCPs' aim to demonstrate culturally sensitive care. Cultural humility implies that learning about different cultures, their practices, values and beliefs is an ongoing life-long process (Kirmayer, 2012; Tervalon & Murray-Garcia, 1998). Demonstrating cultural humility is to acknowledge that culture is ever-changing while encouraging reflexivity, self-awareness and respect for others (Kirmayer, 2012). Although both cultural competence and cultural humility share the same aim of achieving cultural sensitivity, that is demonstrating understanding and respect when working with diverse groups

(Foronda, 2008) and delivering equitable care, their approach is vastly different (Fisher-Borne, Cain & Martin, 2015). Cultural competence focuses on acquiring and applying empirical knowledge while cultural humility uses the approach of self-awareness and takes into account contextual factors and relationships that affect cross-cultural interactions (Fisher-Borne, Cain & Martin, 2015; Tervalon & Murray-Garcia, 1998).

However, cultural humility and cultural competence alone are not sufficient to provide equitable care (Kirmayer, 2012). The HCP must move beyond knowledge acquisition and self-awareness, and instead focus on applying these skills to create a safe health care environment by promoting cultural safety. Cultural safety focuses on creating an equitable environment that is free of discrimination by recognizing and addressing power imbalances in the health care system (Kirmayer, 2012; First Nations Health Authority, n.d). Thus, building cultural humility and cultural sensitivity facilitates the development of cultural safety in health care (First Nations Health Authority, n.d.).

Developing cultural humility among HCPs and creating cultural safety within the health care system supports the palliative approach, as it moves beyond a medical approach to care and takes into account the context of the situation and psychosocial needs. Cultural safety encourages HCPs to be self-reflective, open-minded and respectful, as well as aware of the influence of the client's culture on the care experience. In pursuing a palliative approach, open communication between care providers and clients is encouraged, which allows clients to be more engaged, identify goals of care and understand their experience (Bacon, 2012).

Pursuit of a palliative approach is further supported by The Way Forward Initiative led by the CHPCA (CHPCA, 2015). This initiative works to encourage the integration of a palliative approach across sectors. It outlines The National Framework for an integrated palliative approach and identifies the importance of providing equitable access to culturally sensitive services (CHPCA, 2015). The Way Forward Initiative also aims to build a common understanding of the palliative approach while respecting differing cultural attitudes and perspectives on death and dying (CHPCA, 2015).

While The Way Forward initiative and the available resources, such as the CHPCA Square of Care (2015) framework and the Registered Nurses' Association of Ontario (2007) best practice guideline on cultural competency, are helpful in developing a wholistic approach to care, they do not address the palliative and EOL care needs of specific cultures. Given that the Canadian health care system caters to a widely diverse population, it is important to consider whether the palliative approach has been or can be adapted to different cultural contexts. In order to do so, a more in-depth understanding of specific cultures in the context of the palliative experience must be developed.

This study is a step towards helping HCPs to develop cultural humility by highlighting cultural differences between the South Asian culture and Canadian culture within the context of a palliative approach. By gaining an understanding of the South Asian experience of the palliative approach and highlighting the gaps in care, goals can be set to overcome these gaps in care in an effort to create a culturally safe environment for the South Asian population needing a palliative approach to care.

Research Purpose

The purpose of this study was to explore and understand the experience of bereaved South Asian immigrant caregivers of dying family members. This study explored different factors influencing their experience as caregivers. Challenges and barriers specific to the experience of South Asian caregivers of dying family members were identified. The study especially explores the influence of culture and the role it plays in the caregivers' experience within the context of a palliative approach to care. This study is important because it helps HCPs and decision makers understand the experience, challenges and needs of the South Asian population. It informs the development and improvement of culturally sensitive palliative and EOL care services and resources. Finally, findings from this study have the potential to inspire research related to cultural groups and the building of palliative and EOL care resources that will better serve a diverse community.

Self-Reflection

My experience with the palliative approach to care began early on during the pursuit of my undergraduate degree and continued into my career. Having worked as a registered nurse on an in-patient palliative care unit and in a hospice, I was able to gain the skills I needed to provide quality care for my patients, recognize signs of distress and manage EOL symptoms. As a result of my experience, I came to appreciate the value of communication with the patient and family and the wholistic palliative approach to care. I realized that a palliative approach to care extends well beyond the death of the patient into the bereavement period for the family. As a result, I made efforts to always be inclusive of family members while remaining respectful of the patient’s wishes and family dynamics.

While I gained knowledge and skill in the delivery of a palliative approach to care through my professional experience, I developed a deeper appreciation for it with the passing of a loved one in my family. However, I quickly realized that my understanding of a palliative approach to care, high quality EOL care and my perception of a good death was not shared among my South Asian family. My family members demonstrated little knowledge about the palliative approach and perceived the comfort care approach to be hastening the death of our beloved aunt. Witnessing my aunt’s decline in health, her inability to communicate and inability to eat made them feel helpless and uncomfortable. Being told that it was unsafe or inappropriate to feed her given her physical state made many family members feel as if they were starving her to death. Some of my family members felt that they had failed as a caregiver and blamed themselves for my aunt’s deteriorating health condition. I could see that the stress of decision-making caused more grief and conflict among our family members.

As one of the only members in the family with palliative care experience, I felt that it was my responsibility to educate my family members when possible. Despite my efforts to advocate for the health care team’s palliative approach and our loved one’s care, I recognized that my family members’ ideas of death and dying were starkly different. As such, I found myself caught between two contrasting worlds. As a nurse I understood the palliative approach, the reasoning behind the health care team’s decisions and I was able to recognize a good death, as it is defined in the medical community. In contrast, as a

South Asian immigrant, with parents that uphold strong South Asian cultural values and perceptions, I was also able to understand why many of my family members felt that our loved one was not given a good death. It was clear that the North American definitions of “good EOL care” and a “good death” were not always synonymous with that of other cultures.

Clearly, there were significant differences between the North American culture of care and the South Asian culture of care. It appeared as though the two cultures were incompatible in the field of health care. It was this dichotomy between the two cultures that sparked my interest in the research topic. My personal and professional experiences have highlighted the conflict between cultures and the influence it has on the outcomes of care. While there is some evidence exploring the experience and perceptions of palliative care among ethnic minority groups, there was little literature that had an in-depth focus on South Asian culture. In addition, there was minimal evidence that discussed perceptions of family caregivers and the challenges they encountered when trying to advocate for a good death for their family members while trying to uphold their culture in a Western society. Without this evidence, health care teams cannot effectively support South Asian patients and families through the palliative experience. I wanted to better understand the impact cultural differences have on health care experiences of South Asians and help bridge the cultural gap that often impedes the building of therapeutic HCP-client relationships. Therefore, I decided to focus my thesis on the experience of bereaved South Asian family caregivers.

CHAPTER 2

LITERATURE REVIEW

Overview of the Literature Review

This literature review provides an overview of the available literature outlining the experiences of South Asians receiving palliative care. The studies included in this literature review specifically address the South Asian perceptions of death and dying and the factors that affect the experience of South Asian patients and families who receive a palliative approach to care. This literature review will begin with a description of the search strategy and the inclusion-exclusion criteria that were applied. It will provide a summary of the studies that met the inclusion-exclusion criteria. The summary will outline the perceptions of death and dying among South Asians, experiences of South Asians receiving a palliative approach to care and the role of South Asian caregivers in a palliative approach to care. The aim of this literature review is to synthesize literature related to the South Asian perception of death and dying and their experiences in receiving a palliative approach to care.

Search Strategy

The following electronic databases were searched: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE, PsychInfo and Google Scholar (n=209). Reference lists of articles were also searched. The Journal of Palliative Medicine and Palliative Medicine journal were hand searched. The search terms included variations of the following: *palliative care, end-of-life care, South Asian(s), caregiver(s), caregiver burden, caregiver stress, family caregiver(s),* and *death and dying* (see Appendix C for list of Search Terms). The search terms also included the names of specific South Asian countries. The search was conducted by one reviewer (the author).

Studies were included if they met the following criteria: (a) peer reviewed; (b) written in English; (c) published from 1997 to 2017; (d) discussed aspects of a palliative approach to care, including advance care planning (ACP); (e) focused on the palliative experience of adult South Asians; (f) and focused on South Asian immigrants or diasporas. Studies that did not sample South Asian immigrants or the South Asian diasporas were excluded to ensure the information was specific to the South Asian immigrant experience. Studies were also excluded if they discussed the experience of caregivers of children.

Qualitative articles were assessed for quality using the Critical Appraisal Skills Program (CASP) checklist for qualitative studies (Critical Appraisal Skills Programme, 2017). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist was used to evaluate quantitative studies (von Elm et al., 2014). Systematic reviews were assessed using the CASP Systematic Review Checklist (2017). Given the paucity of literature on the topic, certain studies were included despite having poor to mediocre methodological rigour if: (a) the findings contributed important and relevant information related to the experiences of the South Asian population or; (b) they addressed the experience of the South Asian population living in Canada.

Search Results

A total of 20 studies met the inclusion criteria for this literature review (see Appendix D for a list of included studies). There were 16 qualitative studies, two quantitative studies and two systematic reviews that focused on the South Asian diaspora population's perceptions of death, dying and palliative care, as well as the population's experience of palliative care. Single studies that discussed the HCPs' perspectives (n=8) were included as they provided insight into the needs and experiences of South Asian patients and families. A majority of the studies were conducted in the United Kingdom (UK) (n=9). Studies were also conducted in the United States of America (USA) (n=6) and Canada (n=3). Two systematic reviews were also found. One systematic review focused on the EOL care for all ethnic minorities, including South Asians, in the UK (Evans et al., 2012). The second systematic review focused on the role of spirituality in palliative care in India (Gielen, Bhatnagar & Chaturvedi, 2016).

Perceptions of Death and Dying Among South Asians

Culture significantly influences an individual's actions, ideologies, beliefs and values. It also impacts socio-political structure and social norms. Therefore, cross-cultural interaction and communication presents many challenges, especially when cultural ideologies are misunderstood. South Asian immigrants often face communication challenges within the health care system when receiving a palliative approach to care, as evidenced by the literature (Biondo et al., 2017; Con, 2017; Radhakrishnan, Saxena, Jillapalli, Jang & Kim, 2017; Randhawa, Owens, Fitches & Khan, 2003; Somerville, 2001; Spruyt, 1999; Weerasinghe & Maddalena, 2016; Wilkinson et al., 2016; Worth et al., 2009).

It is important to acknowledge that the term South Asian is encompassing of many sub-groups that may differ in their religious faiths and socio-cultural ideologies.

However, this review of the literature highlights some of the most common and overarching themes that describe the South Asian perspective and experience of the palliative approach.

Death as a Taboo Subject Among South Asians

The topic of death and dying is considered to be taboo among the South Asian community and it is often avoided in conversation for fear that it would hasten death (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017; Spruyt, 1999; Venkatasalu, Arthur & Seymour, 2013; Worth et al., 2009). Venkatasalu et al. (2013) conducted a constructivist grounded theory study with strong methodological rigour to explore and explain the perspectives on death and dying among older South Asians living in East London. The study found that the South Asian community generally avoided talking about death for two major reasons: it was the cultural norm and to protect family members from emotional burden and distress (Venkatasalu et al., 2013). This finding is echoed in other studies that focus on different aspects of the palliative approach to care among South Asians (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017). Biondo et al. (2017), Radhakrishnan et al. (2017) and Con (2007) used qualitative methods to explore the perceptions of ACP among South Asians and found there was poor engagement in ACP due to avoidance of the topic of death. Conversations regarding death were preferred to be had only when required (i.e., when an individual was nearing the end of life) (Biondo et al., 2017; Venkatasalu et al., 2013). Furthermore, South Asian groups felt that having these conversations before it was deemed necessary would elicit negative feelings and be emotionally difficult for the person, as well as their family

(Biondo et al., 2017; Spruyt, 1999; Venkatasalu et al., 2013). Thus, both parties often omitted the topic of death from conversation to avoid burdening each other. This is important because it has an impact on the ability of HCPs to discuss care options with South Asian clients and pursue a palliative approach early on in the disease process.

Although many of the included studies address South Asian perspectives on death and dying, they were not inclusive of all South Asian sub-groups. One study by Spruyt (1999) only focused on the experience of Bangladeshi people living in the UK. Thus, the transferability of the findings is inherently limited. However, the findings of Spruyt are consistent with findings of several other studies, suggesting that there are some commonalities among all South Asian sub-groups. In addition, the aforementioned studies overall have medium to strong methodological rigour further increasing the strength of the results.

Familial Responsibility and Social Dynamics

The role of family in healthcare is prominent among the South Asian population. There is an expectation that family members will take on the responsibilities of making important health care decisions, especially in the EOL (Biondo et al., 2017; Venkatasalu et al., 2013). Elderly South Asians in the study by Venkatasalu et al. (2013) stated that they trusted their families to make the most appropriate decisions, based on the circumstances. The idea of filial piety is also prominent within South Asian communities, as children are often expected to transition into caregiver roles for parents and elderly family members (Radhakrishnan et al., 2017; Venkatasalu et al., 2013; Weerasinghe & Maddalena, 2016).

In contrast, Sharma, Khosla, Tulsky and Carrese (2012) found that some South Asian immigrants did not expect their children, who were well-assimilated into American culture, to fulfill this filial duty for fear of burdening their children. This finding suggests that South Asian immigrants may have difficulty reconciling their traditional beliefs with that of Western culture. In addition, the degree of assimilation can also have an effect on how much an individual adheres to traditional beliefs, thereby affecting their cultural perception of death.

Gender roles. Literature indicates that male children or family members are traditionally expected to take on the responsibility of making important health care decisions for the patient, as a means of reducing the burden on the patient (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017; Sharma et al., 2012; Weerasinghe & Maddalena, 2016). South Asian males often withheld health care information from their wives and women in the family (Con, 2007; Somerville, 2001) to avoid causing them emotional distress (Somerville, 2001). However, the findings of Sharma et al. (2012) suggest that there are generational differences in how these gender roles are perceived, especially among second-generation South Asian immigrants. Regardless, the evidence indicates that gender roles influence the transfer of health care information and the dynamics of the patient-client relationships to some degree. However, there is a need for more rigorous research to support this finding.

Generational differences. Three qualitative studies acknowledged the generational differences in the experience of palliative care (Randhawa et al., 2003; Sharma et al., 2012; Venkatasalu et al., 2014). The status of an individual as first-generation or second-generation had different impacts on their perception of death and dying, the influence of religion on their perceptions, the importance of the place of death and their overall experience in palliative care (Randhawa et al., 2003; Sharma et al., 2012; Venkatasalu et al., 2014). There were several cultural ideas that were upheld among both generations, including the sense of filial duty and perceptions of death and dying (Sharma et al., 2012). Both generations struggle with reconciling South Asian culture with Western culture and upholding traditional beliefs (Sharma et al., 2012; Venkatasalu et al., 2014). However, there are some differences in their experience and how they understand palliative care (Randhawa et al., 2003; Sharma et al., 2012). For instance, Sharma et al. (2012) found that first-generation South Asians did not expect their children to care for them because of lifestyle differences and American culture, yet second-generation South Asians felt strongly about caring for their elderly parents (Sharma et al., 2012). Regardless, it is evident that there is a fear of losing cultural heritage among South Asians, as both first and second-generation South Asians struggle with upholding the culture in a Western society (Venkatasalu et al., 2014).

Influence of Religion & Spirituality

Religion was also a significant factor influencing South Asians' perspectives on death, dying and the palliative approach. Religion often guided the definition of a "good death". Several studies acknowledge the influence of religion on how South Asians make decisions about their health and illness (Biondo et al., 2017; Con, 2007; Doorenbos & Nies, 2003; Gielen et al., 2016; Khosla, Washington & Regunath, 2016; Venkatasalu, Seymour & Arthur, 2014; Worth et al., 2009). Religion appears to influence health care decisions associated with palliative care ranging from ACP (Biondo et al., 2017; Doorenbos & Nies, 2003; Gielen et al., 2015; Khosla et al., 2016) to symptom management (Khosla et al., 2016; Sharma et al., 2012) and place of death (Somerville, 2001; Venkatasalu et al., 2014). Health care decisions were often guided by religious beliefs and faith that the patient's fate was in God's hands (Biondo et al., 2017; Gielen et al., 2015; Khosla et al., 2016; Sharma et al., 2012). However, it is important to note that the religious context may vary between communities and persons. Therefore, the findings of the literature are not conclusive but can improve our understanding of the role religion can potentially play in the South Asian perception of death and dying.

The role of God in illness and death is accepted and prominent among many South Asian communities (Biondo et al., 2017; Con, 2007; Gielen et al., 2016; Kristiansen et al., 2014; Worth et al., 2009). God is seen as the ultimate being with the power to will an illness upon a person or cure the illness (Biondo et al., 2017; Gielen et al., 2016; Kristiansen et al., 2014). The idea of hope was driven by faith in God and ultimately God was the only one who could decide when death was to occur (Biondo et al., 2017; Kristiansen et al., 2014; Worth et al., 2009).

The belief that death is in the hands of God is common among the Hindu, Muslim, Sikh and Christian religions (Gielen et al., 2016) and had significant implications in the acceptance of the palliative approach and engagement in ACP. Palliative strategies and ACP were sometimes construed as unnatural or contradictory to the belief that God was the only one who could control the course of the illness, the time of death and how death was to occur (Biondo et al., 2017; Kristiansen et al., 2014).

Pain and symptom management. The rigorous multi-method qualitative descriptive study by Khosla et al. (2016) found that spiritual beliefs influenced the patients' decisions to use pain medications. Overall, South Asians that adhered to the Hindu, Buddhist or Islamic faith were likely to be more conservative or reluctant in their use of narcotics (Gielen et al., 2016; Khosla et al., 2016). Although the study by Khosla et al. (2016) explored the HCPs' perspectives of providing pain management for South Asian patients in end-of-life, it provided insight into the importance of considering the potential impact of religious or spiritual beliefs. These findings are further substantiated by a systematic review by Gielen et al. (2016), as both pieces of literature highlight the influence of religion and spirituality in pain management strategies and perceptions of pain. However, the systematic review's findings, while addressing several religious faiths, were only reflective of people from India (Gielen et al., 2016). Religion and spirituality are significant in all aspects of an individual's life and care, including their relationships, values, identity and decisions (Gielen et al., 2016). Patients' perspectives on pain management varied based on their religious belief, as some religious faiths suggested pain was a form of karma or punishment that must be endured to atone for their sins (Gielen et al., 2016; Sharma et al., 2012). Furthermore, upholding religious beliefs and practices was sometimes a higher priority than symptom or pain management (Gielen et al., 2016).

The Importance of Environment in Death and Palliative Care

The environment, particularly the home, is of significant value to the South Asian culture and the palliative care experience (Doorenbos, 2003; Owens & Randhawa, 2004; Somerville, 2011; Venkatasalu et al., 2014). According to a study of Asian-Indian immigrants by Doorenbos (2003) 86% of survey respondents reported that they would prefer to die in the home. The rigorous qualitative study by Venkatasalu et al. (2014) discusses the importance of dying at home for elderly South Asians in the UK. After conducting several one-on-one interviews and focus groups, the authors found that dying at home had important cultural and religious implications (Venkatasalu et al., 2014). The home was considered a spiritually significant place (Somerville, 2001; Venkatasalu et al., 2014) and dying at home would allow people to carry out religious rites and rituals allowing for a good death (Venkatasalu et al., 2014). Furthermore, the presence of a supportive environment and ample family support were seen as important to the experience of death (Owens & Randhawa, 2004). However, it is important to note that the study by Venkatasalu et al. (2014) did not include all faiths that are commonly followed within the South Asian community. Therefore, the study results may not reflect all of the South Asian population or all religious faiths.

Conversely, Venkatasalu et al. (2013) found that older South Asians avoided talking about death and dying in the home fearing that they would negatively impact any significant religious or other events taking place at home. The study by Venkatasalu et al. (2013) demonstrated stronger methodological rigour than that of the other studies, as they employed two data collection techniques, interviewed people of varying South Asian countries of origin and in several South Asian languages. Thus, the findings of the study are reflective of a diverse South Asian group. However, the difference in findings among the literature suggests that there is a need for more research regarding the significance of the environment in death within South Asian culture.

Summary Perceptions of Death and Dying Among South Asians

Overall, it is evident that the South Asian community has a different perception of death than that of Western cultures. Death and dying is generally considered a taboo subject, which affects the South Asian community's ability to understand palliative care and engage in ACP. However, the paucity of literature on the subject and the range of study quality indicate that there is a significant need for more rigorous research on this subject. In addition, some of these studies only provide a HCP perspective on the topic (Khosla et al., 2016; Kristiansen et al., 2014; Owens & Randhawa, 2004; Radhakrishnan et al., 2017). While these studies contribute important information, they make assumptions and interpretations about South Asian culture from the perspective of HCPs who may be unfamiliar with the culture. This reinforces the need for research that directly explores the perspectives of South Asian communities.

Most of the aforementioned studies were conducted in the UK or USA and some findings may be transferable to the South Asian population in Canada. However, there are undeniable differences between Canada and other countries, such as culture, laws and the health care system that have the potential to influence the South Asian immigrant experience in significant ways. There is a need for research that explores South Asian Canadian immigrant viewpoints and highlights the possible differences and nuances in Canadian culture that may impact the palliative care experience of South Asian immigrants in Canada.

Experiences of South Asians Receiving a Palliative Approach – Challenges and Barriers

It is evident that South Asians hold different values and beliefs with regards to death and dying than Western culture. Therefore, South Asian immigrants experience a culture clash when receiving palliative care and struggle to reconcile their beliefs with that of Western cultural ideologies. As such, South Asians face several challenges and barriers that prevent them from benefiting from the overall goal of a palliative approach.

There are eight single studies (Khosla, Washington, Shaunfield & Aslakson, 2017; Khosla et al., 2016; Owens &Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Spruyt, 1999; Weerasinghe & Maddalena, 2016; Worth et al., 2009) and one systematic review (Evans et al., 2012) that explore the experiences of South Asians receiving palliative care. These studies explore the topic from the perspective of the South Asian community or HCPs. The literature suggests that factors affecting the delivery of care are: (a) a lack of awareness of the palliative approach; (b) different communication styles and; (c) relationships with health care providers. The literature related to each of these factors is described below.

Lack of Awareness of the Palliative Approach

There is a general lack of awareness about the purpose and need for palliative care as well as the availability of palliative resources among the South Asian community (Biondo et al., 2017; Doorenbos, 2003; Evans et al., 2012; Khosla et al., 2016; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Wilkinson et al., 2016; Worth et al., 2009). Literature also suggests that patients were unaware of the benefits of palliative care strategies and their options for care (Khosla et al., 2016; Wilkinson et al., 2016). For example, Doorenbos (2003) found that only 12% of the survey respondents knew about the option for hospice as a place to receive palliative care and only 22% understood the purpose of a hospice. The qualitative descriptive study by Khosla et al. (2016) found that South Asian patients and families were unaware of the benefits of pain medication and its impact on one's quality of life. A lack of awareness of care needs can be a result of language barriers or failure of HCPs to engage South Asian clients in EOL care conversations (Doorenbos, 2003; Evans et al., 2012; Venkatasalu et al., 2013). Thus, South Asians have difficulty in effectively asking questions, clarifying information and becoming informed about the palliative approach to care. Furthermore, they remain unaware of the availability of palliative and EOL care resources or remain unable to access them.

Advance Care Planning. The influence of culture, family and religion directly impact how the South Asian community understands ACP and the extent to which they engage in ACP. There is an overall lack of engagement, awareness, understanding and knowledge regarding ACP (Biondo et al., 2017; Radhakrishnan et al., 2017). Doorenbos and Nies (2003) surveyed 45 Hindu Asian Indian immigrants in the USA and found that only 9% of the surveyed participants had completed a living will. The results also suggested that when more family members were involved in the care and decision-making processes, there was less likelihood of advance directive completion (Doorenbos & Nies, 2003). However, the survey also suggested that 44% of participants were interested in completing an advance directive (Doorenbos & Nies, 2003). Despite the fact that some South Asians express interest in ACP, there are practical barriers that prevent them from pursuing this interest. Biondo et al. (2017) reported difficulties with translation and conveying information as there was no literal translation for the term "advance care planning" in Hindi, Punjabi or Urdu. Moreover, given that death is considered a taboo topic (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017; Spruyt, 1999; Venkatasalu et al., 2013; Worth et al., 2009) there is little to no awareness of ACP and its benefits. Therefore, ACP has remained a foreign concept among the South Asian community (Biondo et al., 2017).

Literature also suggests that the involvement of family not only impacts palliative care or health care decisions, but also deters individuals from engaging in ACP activities (Doorenbos, 2003). There is an expectation that children or close relatives will become caregivers of elderly family members and take on the responsibility of making care decisions (Biondo et al., 2017; Radhakrishnan et al., 2017). Therefore, patients do not see a need to discuss ACP or complete advance directives since they trust their family members to make the most appropriate decisions for all parties involved. Religious beliefs also deterred people from engaging in ACP, as it was considered to contradict the natural process of death under God's will (Biondo et al., 2017; Doorenbos & Nies, 2003; Weerasinghe & Maddalena, 2016).

Different Communication Styles

Communication is arguably one of the most significant challenges faced by the South Asian diaspora receiving palliative care (Biondo et al., 2017; Khosla et al., 2016; Khosla et al., 2017; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Venkatasalu et al., 2013). Culture largely influences communication strategies and often determines communication styles (Khosla et al., 2017; Venkatasalu et al., 2013). Given that the South Asian culture generally avoids conversations regarding death and dying (Biondo et al., 2017; Radhakrishnan et al., 2017; Venkatasalu et al., 2013), discussing palliative care options with HCPs and receiving high quality care becomes a challenge (Khosla et al., 2017). One study by Randhawa et al. (2003) indicated that some South Asians were satisfied with their communication experiences with HCPs. However, this finding is likely attributed to the inclusion of well-assimilated English-speaking second-generation South Asians in the study sample. Therefore, the transferability of the results is threatened, as this finding is likely not representative of the South Asian diaspora experience. Regardless, it is evident through the literature, that communication is an overwhelming challenge among the South Asian diaspora.

Language barriers. The South Asian diaspora consists of individuals who descend from countries in which the primary language is not English. Therefore, some immigrants experience poor English proficiency which impacts their ability to communicate efficiently with HCPs (Evans et al., 2012; Owens & Randhawa, 2004; Randhawa et al., 2003; Spruyt, 1999; Worth et al., 2009). Being unable to speak English acts as a barrier to accessing services, communicating patient or family needs, engaging in ACP, understanding the illness, and receiving high quality health care (Biondo et al., 2017; Evans et al., 2012; Venkatasalu et al., 2013; Worth et al., 2009).

It is important to note that this literature is limited by the fact that it is not inclusive of all South Asian sub-groups, as this is not always feasible within a research study. In addition, some studies failed to acknowledge important demographic information that could affect health outcomes. For example, whether participants were first or second generation immigrants and the age at which they immigrated were not acknowledged in some studies (Radhakrishnan et al., 2017; Randhawa et al., 2003; Spruyt, 1999; Venkatasalu et al., 2013), despite the fact that these factors influence communication skills and the ability to access resources. One study (Radhakrishnan et al. 2017) acknowledged socioeconomic status and education, as these are important predictors of health outcomes (Government of Canada, 2018), thereby increasing the credibility of the results.

Relationships with Health Care Providers

The experiences of HCPs can also provide important insight into the South Asian experiences of palliative care. HCPs working with the South Asian population face challenges and barriers that prevent them from delivering optimal care to their patients and families. A total of eight studies discussed the experiences of HCPs working with South Asian patients, the challenges in providing care, and their insight into the experience of health care for South Asians (Owens & Randhawa, 2004; Khosla et al., 2016; Khosla et al., 2017; Kristiansen, et al., 2014; Radhakrishnan et al., 2017, Randhawa et al., 2003; Wilkinson et al., 2016; Worth et al., 2009).

A recent study by Khosla et al. (2017) explored the challenges faced by HCPs caring for South Asian patients and families. The study confirmed previous findings in the literature that suggest that communication difficulties largely stem from language barriers and poor interpretation (Evans et al., 2012; Khosla et al., 2017; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Spruyt, 1999;

Worth et al., 2009). In order to combat challenges in communication, translation services are often provided. However translating information was difficult and often inaccurate (Biondo et al., 2017; Evans et al., 2012; Khosla et al., 2017; Radhakrishnan et al., 2017; Spruyt, 1999). Literal translations for key terms such as "ACP" and "palliative" were unavailable in some South Asian languages (Biondo et al., 2017; Evans et al., 2012).

In addition, differing communication styles and the involvement of multiple family members made communication more difficult (Khosla et al., 2017). Sometimes translation services were not easily accessible or were resisted by families (Khosla et al., 2017). Often, it was the patient or other family members who were employed as translators, as this was a more comfortable option for the family (Owens & Randhawa, 2004; Spruyt, 1999; Worth et al., 2009). However, this strategy presented many ethical and practical challenges. Employing the patient or the family member as a translator would place a burden upon these parties to be physically available and reliable to translate sensitive information (Spruyt, 1999; Worth et al., 2009). In addition, family members may withhold information from the patient (Khosla et al., 2017; Sharma et al., 2012). Overall, HCPs expressed a sense of great difficulty with communication, which affected their ability to provide accurate information, appropriate services, and meet the needs of patients with poor English proficiency (Khosla et al., 2017; Radhakrishnan et al., 2017; Randhawa et al., 2003; Wilkinson et al., 2016).

Cultural awareness. Literature also suggests that HCPs demonstrate poor cultural awareness in their approach to palliative care (Khosla et al. 2017; Weerasinghe & Maddalena, 2016; Worth et al., 2009). Food, clothing and social practices are among the many cultural considerations that South Asians have identified as important aspects of care that need to be acknowledged by HCPs (Weerasinghe & Maddalena, 2016; Worth et al., 2009). While HCPs acknowledge that culture is an important aspect of the care experience, there is uncertainty in how to approach conversations about culture and the extent to which it should be acknowledged (Owens & Randhawa 2004). Reconciling the philosophy of palliative care with cultural needs and practices of the patient is also a challenge for HCPs (Khosla et al., 2017; Owens & Randhawa, 2004). There is concern that existing cultural knowledge or awareness may inadvertently lead to stereotyping of the South Asian community, thereby making HCPs uncertain in their approach (Owens & Randhawa, 2004; Worth et al., 2009). The lack of training and education in the area of cultural awareness and sensitivity, as well as the lack of awareness of existing education opportunities also leads to poor cultural sensitivity among HCPs (Worth et al., 2009), thereby impacting the experience of South Asian clients.

Summary of South Asians' Experiences with Receiving a Palliative Approach to Care

South Asian patients and families face several barriers and challenges that prevent them from receiving quality palliative care, as evidenced by the literature. Communication barriers, a lack of awareness and fundamental cultural differences are among the most significant challenges. There are few rigorous studies that explore these challenges, leaving some gaps in the literature. While the aforementioned studies address the experience of South Asian diaspora, the level of assimilation or acculturation is not considered in all studies. It may be acceptable to assume that individuals who are well-assimilated will have had ample opportunity to become accustomed to Western culture and the health care system. In addition, most of the literature does not address whether the participants had experienced receiving palliative care, the degree to which they were involved in the care experience or whether they witnessed someone receiving palliative care. The participant's role in their palliative care experience and their level of exposure to palliative care will affect their overall experience and perceptions of palliative care. Therefore, there is a need for literature that addresses these important gaps to build a stronger body of knowledge regarding the South Asian experience of palliative care.

The Role of South Asian Caregivers in a Palliative Approach to Care

The literature search also focused on the experience of South Asians who are family and friend caregivers to patients receiving palliative care. Only two qualitative studies were found outlining the experience of South Asian caregivers (Somerville, 2001; Weerasinghe & Maddalena, 2016). The study by Weerasinghe and Maddalena (2016) employed several qualitative methods to explore the experience of South Asian caregivers in providing care for their terminally ill family members. The study sample was from the South Asian immigrant population residing in Halifax, Nova Scotia. Seven individuals who identified as primary caregivers participated in semi-structured interviews. Weerasinghe and Maddalena found that caregivers struggled to adhere to their cultural values, practices and beliefs within Western society. Caregivers also referred to the need for mediation between the family caregivers and HCPs. Mediation was required because HCPs demonstrated Canadian values and ideas when providing care which conflicted with South Asian values. Finally, caregivers felt that communication styles and strategies employed by HCP were insensitive to their culture and the family.

Weerasinghe and Maddalena (2016) provided important information regarding the experience of South Asian caregivers, but the study quality was very poor, with several methodological limitations. The study did not specify a specific design, and data collection and analysis strategies were not well-described. In addition, the study was conducted in a geographic location with a small South Asian population and recruited only seven South Asian caregivers. The sample consisted of mostly male participants with high socioeconomic status, post-secondary education and good English speaking skills. This small and homogenous sample of participants decreases the transferability of findings to the greater Canadian South Asian population. Furthermore, the experience of South Asians in Halifax will differ from the experience of South Asians living in a more diverse city, such as Toronto.

Recruiting participants from a highly populated city will likely yield a sample that is more diverse in their experiences. Situating this study in Southern Ontario will help with the recruitment of diverse South Asian participants that allows for a comprehensive understanding of the South Asian experience that is more transferable to other communities in Canada. Although the sample is described as being made up of South Asian immigrants, it is important to consider when the participants immigrated to Canada and their level of acculturation. These factors will have an effect on how well they are able to navigate the health care system, their ability to communicate, and understand Canadian culture.

Somerville (2001) used a qualitative exploratory method to understand the experiences of informal Bangladeshi caregivers of terminally ill family members in the UK. The researchers conducted 90 minute interviews with seven family members from five families. Participants were two months to one year post-bereavement. The study found four major themes that described the overall experience of the caregivers: caring, support, communication, and home and family. Respondents felt that caring for their loved one induced physical, psychological, social and financial stress. Caregivers also felt a sense of duty towards their family member but struggled with balancing other familial relationships. Furthermore, the respondents expressed that the professional support they received was of higher quality than the support from relatives. The theme of communication highlights the cultural aspects that are woven into communication styles. Patients refused to share information about their illness with family members for fear of burdening the family. Patients and families also felt that interpreters were not reliable or effective for communication (Somerville, 2001). This is consistent with previous findings of other studies, suggesting that communication and language barriers are one of the most significant challenges faced by South Asian caregivers and their HCPs (Biondo et al., 2017; Evans et al., 2012; Khosla et al., 2016; Khosla et al., 2017; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Spruyt, 1999; Venkatasalu et al., 2013; Worth et al., 2009). Finally, caregivers stated that having their loved at home to die was important for both the family and the patient.

While the overall study had strong methodology, there were several limitations (Somerville, 2001). First, the study only addressed the experience of Bangladeshi caregivers in the UK. While there were consistencies between the findings of this study and other studies that are inclusive of all South Asian sub-groups, the transferability of Somerville's (2001) findings is still limited by its homogenous sample of only Bangladeshi participants. In addition, the small sample size reduces the transferability and dependability of findings.

It is evident that there is a significant lack of literature that outlines the experiences and needs of South Asian family caregivers who care for their dying family members. The existing literature presents several limitations in methodology and transferability of the findings, resulting in a need for further research.

Evaluation of Studies

The studies included in the literature review range in their methodological rigour from weak to strong. There were two systematic reviews that examined palliative care and EOL care experiences and issues among ethnic minorities (Evans et al., 2012; Gielen et al., 2016). Both reviews used multiple databases and provided a description of their search strategies. A table summarizing the included studies was also included (Evans et al., 2012; Gielen et al., 2016). Evans and colleagues' (2012) systematic review used strong methodological rigour overall. However, only studies from the UK were included in the review, thereby limiting the generalizability of the findings (Evans et al., 2012). In contrast, Gielen and colleagues (2012) included studies from various countries, increasing generalizability. However, unlike Evans and colleagues (2012), Gielen and colleagues (2016) failed to use multiple reviewers to determine inclusion of articles and for data extraction, decreasing the overall methodological rigour of the systematic review.

Only two quantitative studies were included (Doorenbos, 2003; Doorenbos & Nies, 2003). Both studies used a person-to-person recruitment strategy which may have resulted in participant coercion. The study by Doorenbos and Nies (2003) had slightly higher methodological rigour than the study by Doorenbos (2003), as Doorenbos and Nies provided more clear description of their data analysis process and used validated surveys to collect data. However, both studies were moderate in their methodological rigour and overall study quality.

A majority of the articles used qualitative methodologies and ranged in their level of quality. Only one of the 16 qualitative studies did not identify the study design that was used (Spruyt, 1999). Spruyt (1999) used qualitative methods for data collection and reported qualitative findings, but did not specify the design used or describe data analysis. Furthermore, the researcher failed to clearly describe data collection procedures. As such, the methodological rigour of this study was particularly weak (Spruyt, 1999).

Several studies used method triangulation (Con, 2007; Khosla et al., 2017; Khosla et al., 2016; Venkatasalu et al., 2014; Venkatasalu et al., 2013; Wilkinson et al., 2016; Worth et al., 2009) and data source triangulation (Con, 2007; Kristiansen et al., 2014; Radhakrishnan et al., 2017; Randhawa et al., 2003; Worth et al., 2009) increasing the trustworthiness of their findings. However, some studies that sampled HCPs were limited by the use of HCPs that had minimal interaction with South Asian patients (Khosla et al., 2016), were only from one discipline (Khosla et al., 2017; Radhakrishnan et al., 2017) or had a limited variety of disciplines included in the sample (Owens & Randhawa, 2004).

Most studies included in this review were of moderate quality. Although they described their study methodology and demonstrated rigour, some studies were unclear or failed to address key aspects of the study such as inclusion-exclusion criteria (Khosla et al., 2016), recruitment (Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Wilkinson et al., 2016; Worth et al., 2009), data collection (Con, 2007; Kristiansen et al, 2014) or data analysis (Biondo et al., 2017; Doorenbos, 2003; Khosla et al., 2017; Randhawa & Owens, 2003; Spruyt, 1999; Weerasinghe & Maddalena, 2016; Worth et al., 2009).

Literature Review Summary

The literature provides an overview of the perception of death and dying among the South Asian community and how it impacts the experience of palliative care. There are several important aspects of South Asian culture that need to be considered when providing palliative care. As a cultural norm, the topic of death and dying is not openly discussed among the community (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017; Spruyt, 1999;Ventkatasalu et al., 2013; Worth et al., 2009), resulting in a poor understanding of the benefits of the palliative approach. In addition, religion, family and the environment are factors that shape how South Asians view death and dying (Biondo et al., 2017; Con, 2007; Gielen et al., 2016; Khosla et al., 2016; Owens & Randhawa, 2004; Somerville, 2011; Venkatasalu et al., 2014; Venkatasalu et al., 2013; Worth et al., 2009). Culture especially influences what South Asian patients and families identify as priorities for care. These priorities may not align with the health care team's priorities for care, hindering the potential for a positive palliative care experience. Apart from cultural differences, the South Asian diaspora have cited several logistical and practical barriers to care. Communication and language barriers are one of the most significant challenges to receiving quality care (Biondo et al., 2017; Khosla et al., 2016; Khosla et al., 2017; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Venkatasalu et al., 2013).

Overall, there is a paucity of literature exploring the experiences of South Asians in palliative care. Most of the existing research was completed in the UK and few studies were conducted in the USA or Canada. Although some of the findings may be transferable, the differences in the infrastructure of the health care system between countries as well as socio-cultural differences and generational differences may impact the overall experience of care. These varying factors may also present different types of challenges and barriers. Furthermore, the existing literature included participants who were proficient in English or included second-generation South Asians. These groups of people are less likely to experience barriers to accessing palliative care and may have differing ideas of South Asian culture. Finally, the literature includes patients and families but very few studies acknowledge that the two roles elicit different experiences within the context of palliative care. As such, there is a need for studies that focus on the South Asian diaspora experience of palliative care and more specifically, on South Asian family or friend caregivers.

Research Questions

Based on the literature, the following research questions were developed: What are the experiences of bereaved South Asian family caregivers of recently deceased adult family members? Secondary questions include: a) What are caregivers' perceptions of the available palliative supports and services? b) What are the challenges and barriers faced by caregivers when receiving a palliative approach to care? c) What is the influence of culture on the caregivers' experiences within the context of a palliative approach? d) What do caregivers believe they would need to meet their personal and cultural needs when receiving a palliative approach to care?

CHAPTER 3

METHODOLOGY

Research Design: Interpretive Description

In order to answer the research questions, an interpretive description (ID) methodology was used. This is a qualitative methodology developed by Sally Thorne (2016) that uses an inductive analytic approach within clinical research to describe, understand and assign meaning to clinical phenomena (Hunt, 2009; Thorne, 2016; Thorne, Kirkham, O'Flynn-Magee, 2004). The methodology of ID was the most appropriate and applicable methodology for this research study because its design enabled the in-depth exploration of a phenomenon specific to the clinical setting and the area of nursing. Specifically, ID provided the appropriate tools and strategies to describe and understand the experience of a vulnerable population, such as bereaved South Asian caregivers, while acknowledging my experience and influence as a researcher on the research process. In addition, ID considers the complexities of the health and illness experiences and acknowledges the importance of clinical context (Hunt, 2009; Thorne, 2016; Thorne et al., 2004).

The methodology of ID is rooted in the constructivist paradigm (Hunt, 2009) as it assumes that all phenomena are subjective in nature and supports the notion that multiple realities exist (Hunt, 2009; Thorne et al., 2004). This method also acknowledges the influence of the researcher on the research process and subject of study (Thorne et al., 2004). Thus, in this study, the researcher's experience and preconceptions inevitably influenced the development of the research question, the chosen research methodologies and the interpretation of the findings (Hunt, 2009). The methodology encouraged the acknowledgement of the researcher's personal assumptions and preconceptions through the process of reflexivity (Hunt, 2009; Thorne et al., 2004), which was demonstrated through the process of memoing. In doing so, the rigour and trustworthiness of the study was increased.

Based on the methodological characteristics of this design, it was apparent that ID was best suited for a study that aimed to explore the clinical phenomenon of the South Asian experience of palliative care. ID provided appropriate strategies that may be employed to gather data that is accurate and reflective of the true experience of bereaved South Asian family caregivers, without devaluing the individuality of the experience or the researcher's contributions to the research process.

Study Setting

The study was set in Southern Ontario, as there is a large cohort of South Asians residing in this geographical location (Region of Peel, 2013; Statistics Canada, 2016).A community hospice and community health centre served as recruitment partners by identifying and referring former and existing clients as potential participants. Both organizations were based in communities with a large number of South Asian clientele accessing their services. The community hospice serves terminally ill clients and their families in the community through the availability of hospice services, community resources, bereavement resources and trained staff. There are 19 staff members and over 150 volunteers within the organization. The community hospice also serves a community with a large South Asian population and has established resources dedicated to the South

Asian community, for example South Asian bereavement support groups. The community hospice is also dedicated to conducting a South Asian Community Engagement Forum to educate South Asians in the community about palliative care. Given their large South Asian client base and their efforts to engage the South Asian community in palliative care education, this community hospice was as an integral partner that helped access potential participants for this study.

The second site was the community health centre, a not-for-profit organization that addresses the social and health care needs of the community through various services. These services include home support, transportation services, family support programs, food services and health services. There are over 155 staff members and over 650 volunteers in the organization. The organization is spread across 11 sites and aims to improve and sustain the health of the community. This community health centre is based in an urban area that has a large South Asian population. Similar to the community hospice, there were a large number of South Asian clients accessing the various services offered by the community health centre. Furthermore, the community health centre also provided palliative care support and bereavement support. Therefore, this community health centre also served as an appropriate partner in accessing eligible participants.

Sampling

A number of different purposive sampling strategies were used. Purposive sampling is a sampling technique used with qualitative methodologies that involves selecting specific participants who have experienced the phenomenon of interest or have the desired characteristics of interest (Creswell, 2013). In this study, purposive sampling methods of criterion sampling, maximum variation sampling and theoretical sampling were used. The method of snowball sampling was also applied by encouraging existing participants to recruit or refer their friends or family who may have undergone a similar experience.

Criterion sampling. For this study, community recruitment partners helped me to gain access to the population of interest and they used their experience in working with the South Asian community to inform strategies for data collection and communication techniques. Specific sets of criteria were used to purposefully recruit participants. Only those individuals who satisfied both sets of inclusion-exclusion criteria were included in the study.

Two sets of inclusion and exclusion criteria were used to determine eligibility. The first set of inclusion and exclusion criteria addressed the characteristics of the participant. The second set of inclusion and exclusion criteria addressed the characteristics of the participant's deceased family member. Participants were eligible for inclusion if they were: (a) first generation immigrants; (b) from Bhutan, Bangladesh, India, Maldives, Nepal, Pakistan or Sri Lanka; (c) directly immigrated to Canada from a South Asian country; (d) identified as a family caregiver for a recently deceased adult family member; (e) bereaved at least two months and; (f) spoke English or another South Asian language for which a translator was available. A third party translator was available for the languages of Hindi, Punjabi, Urdu and Pashto. The primary researcher was able to speak Tamil and served as her own translator.

For this study, bereaved participants were interviewed as opposed to participants who are active caregivers. While there were ethical concerns with interviewing bereaved individuals, these individuals have expressed benefits of engaging in interviews as a method of positive bereavement support and an opportunity to express their feelings and thoughts in a confidential manner (Bentley & O'Connor, 2015; Casarett, Crowley & Hirschman, 2003; Hynson, Aroni, Bauld & Sawyer, 2006). Potential participants who were actively providing care for a family member were not included to avoid introducing additional burden and stress for the participant and their family. Furthermore, evidence suggests that bereaved individuals are willing and prefer to be interviewed shortly after the death, as it allows for better memory recall (Addington-Hall & McPherson, 2001; Bentley & O'Connor, 2015; Hynson et al., 2006).

Participants were excluded if they did not satisfy the above criteria and if they: (a) cared for a family member who was a child at the time of death and; (b) did not immigrate to Canada directly from a South Asian country. The focus on adults was decided as there are significant differences between the palliative approaches for adult and pediatric populations (Committee on Bioethics, 2000; Feudtneret al., 2011; Morgan, 2009), thereby eliciting a different palliative care experience. Participants were eligible to participate if their child was above the age of 18 years old and receiving adult palliative care.

Individuals that immigrate from a non-South Asian country may potentially have adopted a different set of cultural values or beliefs that are not reflective of their South Asian origin. Furthermore, there was no way to determine to what extent these individuals upheld South Asian culture and adhered to cultural practices. Therefore, it was acceptable to assume that individuals who immigrate to Canada directly from a South Asian country were more likely to adhere to their South Asian culture.

Family member inclusion criteria. The characteristics of the deceased family member were also important to consider, as these factors influence the experience of the caregiver. The type of relationship, illness, and care received by the family member inevitably influence the caregiver's experience. In this study, the term family member did not have a strict definition, as the definition of "family" varies between cultures and communities. The identification of an individual as a family member may not refer to the sharing of a common ancestor, but rather to the quality of the relationship. Therefore, the participant defined the term "family member", which could also include a friend or neighbour. In order for the participant to be eligible, the characteristics of the deceased family member met the following criteria: (a) the family member was an adult at the time of death and (b) the family member was of South Asian descent.

Maximum variation sampling. Maximum variation sampling was used to obtain a range of experiences, which increased the richness of the data (Creswell, 2013). Specifically, the sub-type of demographic variation was applied (Sandelowski, 1995). Given that a previous study that explored the caregiver experience only included English speaking participants from India who were male (Weerasinghe & Maddalena, 2016) efforts were made to recruit a more diverse sample that included non-English speaking male and female participants from other South Asian countries. Various relationships including spousal, parent-child and in-law relationships were included. Demographic variation was also achieved by including participants of varying ages, from different South Asian countries, and a varying amount of time in Canada.

Theoretical sampling. Theoretical sampling was informed by concurrent data collection and data analysis (Thorne, 2016; Thorne, Kirkham & MacDonald-Emes, 1997). As themes emerged through the data analysis, the sampling and recruitment strategies were adjusted to meet the needs of the study and in order to explore and explicate the emerging themes. This also helped to ensure that the resulting findings were truly reflective of the phenomenon and accurately captured the participants' experiences. For example, early on in the study, a caregiver from Sri Lanka described stigmas associated with personal support worker (PSW) roles. In order to explicate this emerging idea, I sought to recruit other individuals from the same country to determine whether this was a shared idea within the community.

Sample Size

When emergent designs or methods, such as ID, are employed, sample size is difficult to determine and remains flexible (Patton, 2015). It is often dependent upon the subject of study and the frequency of occurrence of the phenomenon (Thorne, 2016). Previous studies that have focused on the South Asian experience demonstrate a large range of sample sizes (Kalengayi, Hurtig, Ahlm & Ahlberg, 2012; Lasiuk, Comeau & Newburn-Cook, 2013; Maheu & Thorne, 2008; Thorne, Con, McGuinness, McPherson & Harris, 2004; Thorne et al., 2010). For this study, the initial sample size estimate was 15 participants, which was based upon time constraints and recruitment feasibility**.** Ultimately, I recruited 11 participants who met the inclusion-exclusion criteria.

Data Collection

Recruitment

Recruitment occurred with the help of community partners and took place from October 31, 2017 to February 28, 2018. I first met with a representative from each community partner to discuss the purpose of the study and the inclusion-exclusion criteria for the study. Community partners provided an official email statement of their agreement to assist with recruitment. Once ethics approval was received (see Appendix E), I provided each of the community partners with the full research proposal, recruitment pamphlets, and a telephone script used for recruitment (see Appendix F for recruitment pamphlet and Appendix G for telephone script). The community health centre submitted the research protocol for approval under their internal research ethics review board prior to starting recruitment.

Community partners screened their clients based on the inclusion-exclusion criteria and contacted them to inform them about the study. Interested participants consented to release their contact information to the researcher and agreed to be contacted via telephone for more information about the study. I contacted participants and provided them with more information regarding the study, the interview process, consent and confidentiality, and compensation for their time. Individuals who agreed to participate provided a time and location of their choosing and convenience to conduct the interview.

Demographic Data

Demographic information was collected using a demographic form (see Appendix H).The following information was collected for each participant: age, sex, occupation, South Asian nation of origin, age at time of immigration, languages spoken, preferred language, relationship to deceased family member, and number of months bereaved. The form also collected the following information about the participants' deceased family members for whom they were caregivers: age, cause of death, date of death, place of death, and whether death was expected.

While the recruitment partners did their best to ensure eligibility, certain demographic information pertinent to determine inclusion-exclusion was not always available to them. Therefore, the use of the demographic form served as a second screening tool to ensure that participants met the criteria.

Semi-Structured Face-to-Face Interviews

Interviews are a common and effective method of collecting information about a person's experience (Patton, 2015; Thorne, 2016). The primary researcher conducted all the interviews and wrote field notes during the interview. A semi-structured interview guide was used with key questions to guide the interview process (see Appendix I) (Gill, Stewart, Treasure & Chadwick, 2008). The interview guide was developed based on the research questions to address gaps in literature surrounding the experiences of South Asian caregivers. The interview guide was piloted with a South Asian immigrant to identify areas of refinement with regards to language and approach. The interview guide was amended following the first five interviews by adding or modifying questions in order to explicate emerging ideas. A total of 11 interviews were conducted. Interviews were conducted in a place that was deemed convenient, safe and comfortable by the participant. Participants were given the opportunity to choose their location, given that the location of the interview can affect the quality, content and depth of the interview (Elwood & Martin, 2000). Doing so made the participants more comfortable with the interview process (Balls, 2009) and contributed to an overall positive interview experience and likely yielded richer data. In addition, this lessened the burden upon the participant by eliminating travel time and costs. Informed consent was obtained from each participant with translation available as needed. Each interview lasted between 45 to 60 minutes and was audio-recorded.

Translators. Translation services were required for three interviews. Two of the interviews required the service of a third party translator. The translator had no relationship with the participants and was recruited through reference from the community hospice. She was able to provide translation services for the languages of Hindi, Urdu, Punjabi and Pashto. I was able to translate for one participant that spoke only Tamil. The translator also contacted eligible participants that did not speak English in order to set up an interview date and time. Once interviews were complete, the translator was given a Visa gift card as compensation for time.

Prior to engaging in interviews, I engaged the translator in a training session. Evidence suggests that some South Asian languages do not have literal translations for “advance care planning” and “palliative care” (Biondo et al., 2017; Evans et al., 2012), which may present challenges for the translators and decrease the accuracy of the translations. In order to address such issues, the translator was required to complete a one hour training session (Patton, 2015). During training the translator was provided with an overview of the study, details of her role and expectations. The translator also had an opportunity to familiarize herself with the interview guide and the interview process to ensure questions and responses would be accurately translated. The translator also signed a written consent form (see Appendix J) indicating consent to participating in the research process, and to maintain the confidentiality and anonymity of the participants.

Following the end of each interview, the translator and researcher engaged in a short debriefing session. This allowed clarification of any questions regarding the translated responses and to ensure that her perceptions and understanding of the participants' responses was fully explored. This was also an opportunity for the translator to clarify any difficulties or possible inaccuracies in the translation.

Field Notes and Memoing

Written field notes were taken during each interview. Field notes consisted of observations that were made during the interview process (Creswell, 2013). Field notes assisted me in formulating new questions during the interview process and provided additional information, such as non-verbal cues and other observations that assisted with data analysis (Patton, 2015). Notes were also taken on important ideas, emerging questions, key or repeating words or phrases, and personal thoughts or reflections. The field notes also served the practical purpose of acting as back-up data in the case of loss of audio-recordings or technical difficulties with audio recordings (Patton, 2015). The field notes and memos were used to assist in the data analysis process and provided contextual background to the transcripts.

Data Analysis

Data analysis in ID follows an iterative and inductive approach (Thorne et al., 2004). Data analysis occurred concurrently with data collection, using a constant comparative analysis method (Hunt, 2009; Thorne, 2000). Thorne (2016) suggests that the researcher immerse themselves in the data and become familiar with the data. Therefore, I transcribed the audio-recorded interviews verbatim using Microsoft Word Processor. During transcription, identifying information, such as names, was excluded. The transcription was proofread and compared to the audio recording. Demographic information was entered into a password-protected file using the Microsoft Excel Program. The transcriptions and demographic information were then uploaded onto Dedoose Software, an online data management software that is encrypted and password protected (Dedoose, 2018). All paper and electronic files were password protected and filed in a locked cabinet to ensure security.

Coding

Prior to engaging in the coding process, transcripts were read and reviewed several times to immerse myself in the data and become familiar with the emerging ideas to encourage an open mind during analysis and gain a sense of the data that moved beyond the initial impression (Thorne, 2016). This process of immersion and becoming familiar with the transcripts was further aided by memoing and transcribing each transcript myself (Thorne, 2016). The coding process was iterative and emergent in design, and followed the steps of open coding, axial coding and selective coding (Thorne, 2016). Open coding, also known as line-by-line coding, was used to identify basic concepts and characteristics of the data (Thorne, 2016). My supervisor and I independently coded the first three transcripts by hand by highlighting or underlining key words, sentences or quotes, and identifying potential codes. My supervisor and I then met to compare and discuss codes, themes and ideas that emerged. I then coded two more transcripts. Following this, axial coding was used to make connections between open codes, and selective coding was used to create further relationships between the categories to create a conceptual coding framework (Thorne, 2016). I then shared the initial coding framework with my supervisor for feedback and comments. The coding framework and the first three transcripts were shared with the supervisory committee for further feedback, development and validation. Any transcripts that were coded afterwards were coded independently by myself using Dedoose software and verified with my supervisor.

As coding occurred, the coding framework was redeveloped to reflect emerging themes and ideas. Memoing occurred concurrently throughout the coding process. Memos and field notes were referred to during the coding process to identify new codes, reframe existing codes, or to identify codes that required further development. Based on the coding, adjustments were made to the interview guide to ensure that guide reflected codes that required development.

Rigour and Trustworthiness

The methodology of ID shares the philosophical underpinnings of naturalistic inquiry and is based upon these shared principles with other traditions and methodologies (Berterö, 2015; Thorne et al., 2004). As such, rigour and trustworthiness were evaluated using Lincoln and Guba’s (1985) criteria: credibility, dependability, transferability and confirmability. Different strategies were used to meet the aforementioned criteria to enhance the rigour of the study.

Credibility

Credibility refers to the extent to which the findings accurately capture and reflect the responses of the participant to describe the phenomenon of interest (Lincoln & Guba, 1985; Patton, 2015; Shenton, 2004). To enhance the credibility of the study investigator triangulation was employed. Investigator triangulation was achieved by consulting the thesis supervisor and the thesis committee during data analysis to validate the coding framework and obtain different perspectives on the emerging themes. Credibility was further enhanced by the use of field notes to provide context and support the data collected from the interview. Member checking was not completed as Thorne (2016) "would not recommend this, as it can lead to false confidence" in the findings and prevent the researcher from making their own in-depth analytic interpretations of the findings (p.175).

Dependability

The concept of dependability within qualitative research refers to the consistency of the data and the extent to which the study and results can be repeated (Houghton, Casey, Shaw & Murphy, 2013; Lincoln & Guba, 1985; Patton, 2015; Shenton, 2004). Dependability was achieved by maintaining an audit trail, in the form of memoing and field notes, to ensure that all steps and decisions made throughout the research process were recorded accurately (Thorne, 2016).

In addition, to ensure that there was consistency during data collection, an interview guide was used and participants were asked similar questions. To further ensure consistency, translators were provided with training and a clear understanding of each interview question and its purpose. This ensured that questions and responses were translated with higher accuracy and enabled meaningful interpretations of the data that were accurately reflective of the participants' experiences.

Transferability

The applicability of the findings to other situations is determined by transferability (Lincoln & Guba, 1985; Shenton, 2004). To increase the transferability of the findings, a detailed description of the background of the study, the setting, phenomenon of interest and the participants was provided (Houghton et al., 2013; Shenton, 2004). This was further supported through the maintenance of field notes and memoing (i.e. the audit trail) that provided additional details on the participants, data collection and data analysis.

Confirmability

Confirmability is the degree to which the data analysis and results are free from the researcher's bias and are an accurate reflection of the participants' experiences (Houghton et al., 2013; Lincoln & Guba, 1985). However, the methodology of ID postulates that the researcher's experience, values and beliefs inevitably influence the research study, including the development of the research questions, methodologies employed and data analysis (Thorne et al., 1997). While the research was not completely devoid of researcher bias, it was integral to the rigour of the study that I acknowledged my influence upon the research process and interpretation of the findings. This increased confirmability and overall trustworthiness of the study (Thorne et al., 1997).

Furthermore, confirmability was achieved by maintaining an audit trail and engaging in reflective journal, which was incorporated into the process of memoing. Reflective journaling is a helpful method of acknowledging and documenting my influence on the research process throughout the study (Houghton et al., 2013). Field notes also have a similar benefit (Houghton et al., 2013), in that they documented the developments of the study and my thought processes throughout the interviews and post-interviews. Analyst triangulation also assisted in increasing the confirmability of the study (Patton, 2015; Shenton 2004). To achieve this, the thesis supervisor and committee were consulted throughout the concurrent data collection and data analysis phases. Strategies for data collection, the analysis process, emerging themes in the analysis and other concerns or issues throughout the process were shared and discussed with the committee. An audit trail was used to ensure confirmability (Houghton et al., 2013; Shenton, 2004).

Ethical Considerations

Ethical approval was obtained by the Hamilton Integrated Research Ethics Board (project number: 3896). Ethical considerations were guided by the Tri Council Policy Statement’s principles of respect for persons, concern for welfare and justice (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). The phenomenon of interest deals with sensitive issues and a vulnerable population. As such, there were several important ethical considerations made when working with this vulnerable population. Vulnerable populations are subject to the following risks: distress, exploitation, misrepresentation and identification of the participant (Richards & Schwarts, 2002). In order to combat these potential risks, participants were treated equitably, respectfully and with respect for their right to make autonomous decisions. In addition, the participants' welfare was always prioritized and maintained throughout the study.

Given the sensitive nature of the topic of discussion, the interview had potential to elicit difficult emotions and distress among the participants (Richards & Schwarts, 2002**).** When participants expressed the need for bereavement support, they were referred to the appropriate support services offered by the community hospice or other local supports offered by the community health centre.

Written and informed consent was obtained at the beginning of the interview (see Appendix K) followed by the collection of demographic information. Translators verbally translated the consent form to those who did not speak English. Translators were also asked to sign a consent and confidentiality form during the training session to ensure that they understood their role and maintained the confidentiality of the participant.

Furthermore, evidence suggests that waiting at least two months after death to interview bereaved individuals is ethically sound and appropriate (Addington-Hall & McPherson, 2001;Kaarbø, 2011), given that participants are not forced to participate, have the right to withdraw at any time, and are assured anonymity and confidentiality (Stroebe, Stroebe & Schut, 2003).

Any information that was collected was stored securely. The audio recorders, demographic forms and consent forms were locked securely in a cabinet in the office of the thesis supervisor. Electronic files, such as coded transcripts, were stored as password protected files. All identifying information was removed from the transcripts and was also stored on Dedoose. Any files with identifying information will be destroyed immediately after the completion of the study. All files and data will be stored for five years after the completion of the study and then destroyed after this time period.

CHAPTER 4

FINDINGS

Participant Characteristics

A total of eleven caregivers were interviewed (see Table 1). Female caregivers made up 64% of the sample. The average age of caregivers was 46 years old (SD=15.2), ranging from 21 to 74 years old. All the caregivers were direct immigrants with most caregivers immigrating to Canada from India (36%, n=4) and Sri Lanka (36%, n=4). The remaining caregivers arrived from Pakistan (18%, n=2) or Nepal (9%, n=1). Caregivers had lived in Canada for an average of 17.7 years (SD=15.3), ranging from two to 47 years. Only 18% (n=2) of caregivers did not speak English and required a translator. However, 100% of caregivers (n=11) fluently spoke another South Asian language. During their time as caregivers, caregivers worked an average of 19.3 hours of paid work a week (SD=16.9). At the time of the interview, all caregivers were at least two months bereaved but less than three years bereaved, at an average of eight months bereaved (SD=8.6).

Table 1: Participant Characteristics

	Total (N=11)
Characteristics	***mean (SD)***
Age of Participants in Years	46 (15.2)
Number of Years in Canada	17.7 (15.3)
Hours of Work a Week During Time as a Caregiver	19.27 (16.9)
Number of Months Bereaved	8 (8.6)
	n (%)
Gender	
Male	4 (36.4)
Female	7 (63.6)
Country of Immigration	
India	4 (36.4)

Pakistan	2 (18.2)
Sri Lanka	4 (36.4)
Nepal	1 (9.1)
English Speaking	
Yes	9 (90.9)
No	2 (18.2)
Participants Able to Speak Another Language	11 (100.0)
Highest Level of Education	
High School Diploma	4 (36.4)
College Degree	4 (36.4)
University Degree	2 (18.2)
Graduate Degree	1 (9.1)

Characteristics of Family Members Who Died

Family members who died were spouses (27%, n=3), parents (55%, n=6) or parent-in-laws (18%, n=2) of caregivers. Most family members died in the home (73%, n=8) and the remaining number of family members died in hospital (27%, n=3). Death was expected for most of the family members (73%, n=8). The average age at death was 72 years old (SD=12.9), ranging from 43 years old to 88 years old (see Table 2).

Table 2: Characteristics of Family Member Who Has Died

	Total (N=11)
Characteristics	***mean (SD)***
Age at Death	72 (12.9)
	n (%)
Expected Death	8 (72.7)
Unexpected Death	3 (27.3)
Place of Death	
Home	8 (72.7)
Hospital	3 (27.3)
Hospice, LTC, Other	0 (0)
Relationship to Caregiver	
Parent	6 (54.5)
Spouse	3 (27.3)
Mother-in-Law	2 (18.2)

Overview of Major Findings

The study findings revealed that caregivers had varying and complex experiences, affected by numerous cultural and non-cultural factors. The experiences of bereaved South Asian caregivers was described and explored through five themes: (a) Transforming Perceptions of Life and Death; (b) The Influence of Culture on the Palliative Experience; (c) Challenges of Being a Caregiver; (d) Coping with the Challenges of Caregiving and; (e) Caregivers Receiving Support. Each theme is composed of subthemes that detail the experience (see Table 3).

Table 3: List of themes and sub-themes

Theme	Sub-Theme
Transforming Perceptions of Life and Death	a) "You have to live life, right then and there": An Appreciation for Life b) "She didn't used to think about death, and now she does": Viewing Death and Dying Differently
The Influence of Culture on the Palliative Experience	a) "It's My Duty": The Decision to be a Caregiver b) "I'm not understanding many things because of my language barrier": The Influence of Language on the Palliative Experience c) "It's important to keep them at home in our culture": Living and Dying in the Right Place d) "They never told her she was dying just to keep her hope alive": Protecting Each Other e) "He would not allow any outside help":

	Stigma Against Paid Caregiver Roles f) "For his satisfaction, we made the food": Cultural Role of Food in the Palliative Approach
The Challenges of Being a Caregiver	a) "I do what I can. It's hard sometimes": Finding a Balance b) "I could have done more": The Pressure to be a Good Caregiver c) "We didn't have any clue": Understanding the Experience
Coping with the Challenges of Caregiving	a) "You go towards God and he makes it all easier": Finding Strength in Spirituality b) "It was hard for me, but I blindfolded myself": Blocking it Out c) "Time does heal things": Coming to Terms with the Experience d) "Turn the bad things into positive things": Maintaining a Positive Attitude
Caregivers Receiving Support	a) "The family helped a lot": Relying on Family and Friends b) "We appreciate what they did": Receiving Health Care Provider Support c) "It's not really me, to be honest": Perceptions of Formal Bereavement Support

The theme 'transforming perceptions of life and death' describes the reflexivity demonstrated by caregivers and the changes they experienced with regards to their perspectives, values and thoughts on life and death. The theme 'the influence of culture on the experience' discusses how culture impacted various aspects of the caregivers' experience. Caregivers also described the challenges they faced when caring for their family member, including finding a balance in their daily lives, the pressure they felt to fulfil their role successfully, language barriers, and their lack of understanding regarding the medical aspects of the experience. In trying to cope with these challenges caregivers turned to religion and spirituality, found distractions in hobbies and activities, and tried to overlook the negative aspects of the experience while focusing on the positive aspects. A majority of the support they received came from families and friends, but many caregivers also described receiving support from health care providers, and from external resources, such as bereavement support groups.

Transforming Perceptions of Life and Death

Following the experience of caregiving and the death of a family member, caregivers shared the ways in which their views on life and death have changed. Caregivers' described their ideas on life and death as follows: (a) an appreciation for life and; (b) viewing death and dying differently. The experience provided participants with new insight into themselves, their values or culture. It prompted changes in their lifestyle and behaviours. While specific insights and changes varied among participants, there was a general agreement that the experience had provided them with a greater appreciation for life and altered the manner in which they viewed or discussed death and dying.

“You have to live life, right then and there”: An Appreciation for Life

Caregivers reflected on their experiences and felt that they had a newfound appreciation for life, prompting them to revaluate their values. They reflected on “what life was about and how it works” (Participant 2, Indian Husband). One caregiver felt that as a result of her mother-in-law’s death and her experience as a caregiver, her “outlook towards life and towards people have changed” (Participant 3, Indian Daughter-in-Law). She reflected more deeply on her experience:

> We know that we are going to die, but I question what is important in our life. The value of life, quality of life we have, and we have more appreciation towards life. [We should] enjoy the moments we have with the kids. Nobody knows what [is going to] happen to you. You might be walking, driving, and you don’t know [what is going to happen] and you don’t want to think about those things. So cherish it, the time [and] what you have. (Participant 3, Indian Daughter-in-Law)

This caregiver later shared a meaningful metaphor for her experience that a bereavement counsellor used to help her come to terms with her experience. This metaphor resonated with her personal experience caring for her mother-in-law and coping with her death:

> [On] this side of journey, before entering the jungle, you were different. This journey was your jungle and when you come out of the jungle you are a little bit different. You won’t be the same person who didn’t see the jungle. You are out [and] you will see the new light. (Participant 3, Indian Daughter-in-Law)

Most caregivers were humbled by their experience, often prompting a deep reflection on their values and lifestyle. Caregivers also often chose to focus on the positive outcomes of the experience. One caregiver shared her thoughts and reflections on what matters most in life:

> Money is not important. Real love and care is helping others when they're in need. Even the other day, my brother was asking what I needed, what the kids needed. If I need any help, they will do it. That's what's important. So only if we share that with our kids, they will know what real love is. Parents are the ones who need to tell their kids [this]. (Participant 11, Sri Lankan Daughter)

This caregiver's experience of caring for her mother in the EOL strengthened her belief in the importance of having meaningful and loving relationships in life. Another caregiver shared his powerful revelation as a result of his wife's death, regarding the impermanence of life:

> People used to say you know life is short. Then I realized that sometimes you're fighting with your wife and the day doesn't go by, you know. But everybody says like that, this is the normal life. Then somebody is telling me, 'hey life is short'. But when a day is very hard to pass, how can the life be short? But now I see that [it's true]. She's gone. (Participant 2, Indian Husband)

Although this caregiver was given the advice that "life is short" and that he should appreciate it, he did not heed this advice until his wife's death. This experience helped him understand the perspective that life is short and appreciate the sentiment.

Despite the challenges and sadness their experiences brought, caregivers were able to reflect on their experiences and extract meaningful life lessons. In the case of some caregivers, their reflection on the experience prompted life style changes that would benefit themselves or those around them. Other caregivers were more passionate about changing the culture around caregiving and eradicating the challenges they experienced for future caregivers:

> And now I have the aim of doing the volunteer work… I [want to be] involved somewhere. [It] doesn't matter if it's a little bit. But I know that I have some compassion in me, which [helps me to] understand and connect with people. So [I] can help certain people. That's [why I wanted to participate in] your research. [I hope] my views can help somebody and create less chaos in dealing with things. (Participant 3, Indian Daughter-in-Law)

This caregiver chose to embrace her experience and identified volunteer work and participating in this research study as meaningful ways to help other South Asian caregivers. Overall, caregivers expressed a deeper appreciation for life and its preciousness, as well as hoped for a better future for other South Asian caregivers.

"She didn't used to think about death, and now she does": Viewing Death and Dying Differently

As a result of their experiences, caregivers also re-evaluated their perceptions of death and dying. Experiencing the death of their family members triggered conversations and thoughts about death. Caregivers began to imagine the realities of their own death and contemplate the idea of achieving a good death for their own selves.

Many caregivers felt that the Canadian lifestyle, customs and culture would impact their future care and death. In particular, caregivers did not want to burden their children knowing that they lead busy lives and felt that there was a higher likelihood of being placed in a long-term care (LTC) home. There was less expectation placed upon their children and family members to be caregivers in the same capacity as they had. As one caregiver explained,

> I don't know if my daughter will do the same thing for me. But I will go straight to the nursing home, because I know how hard it is taking care of people. So I think the culture will change (Participant 1, Sri Lankan Daughter).

As a result of her experiences, this caregiver changed the way she envisioned her own death, taking into account cultural differences between South Asian and Canadian culture as well as the challenges of caregiving.

Another caregiver explained the shared notion of accepting the idea that her own death and her children's role as caregivers will look very different in the future:

> I've already prepared myself based on our current situation and how things are here. But we don't want to be a burden to [our children], because they're busy, they'll have a family and we don't want them to get tired of us. We've accepted that, but my parents are different, because they grew up back home, they have the expectation to be looked after by their children. But for us, we've already accepted that it's going to be different. We already know this is how it's going to be. (Participant 11, Sri Lankan Daughter)

This caregiver recognized that the cultural expectation to care for elderly family members would likely become obsolete among her second-generation children living in Canada. She recognized that the difference in lifestyle affected the ability to uphold cultural expectations and ideas. Furthermore, the idea of preparation in order to reduce the ‘burden’ on their children was common among the caregivers with children. Caregivers did not want to ‘burden’ their children but still felt that their children or family should be informed of their wishes.

Some caregivers felt more open to the idea of talking about their death and expressed wanting to share their thoughts with their families. However, they were often met with resistance or reluctance from their family members. One caregiver captured this idea when she explained her husband’s reluctance to imagine a future in which one spouse is dead. She said,

> “He got really mad at me. [He said] ‘Why are you saying that?’ [I said] no, just give me a scenario: what will I do if you are not there and what will you do if I am not there?” (Participant 3, Indian Daughter)

Although some caregivers were able to discuss death and dying more readily, others were still uncomfortable despite expressing interest. Regardless, it was evident that this experience had enlightened them to the realities of death and dying in Canada, leading them to contemplate the idea more deeply.

The Influence of Culture on the Palliative Experience

Culture had an undeniable impact on caregivers’ experiences. However the degree of impact varied across caregivers. The actual importance of culture varied, as caregivers each had their own interpretation of the meaning of culture and its value. Nevertheless, most caregivers agreed that culture was of great importance in their lives. For one male caregiver, culture was important because it was his connection to his home and family:

> Yeah it is important, because we were born [in Pakistan]. And although we live in Canada right now, everything [our culture and lifestyle is] still in our minds. And I am the only person in Canada. So I miss my family and my home as well. (Participant 6, Pakistani Husband)

Many caregivers echoed this sense of loyalty to their culture and the importance of upholding cultural values, despite being surrounded by contradictory or differing cultural attitudes and values. In contrast, there were a few caregivers that identified as ‘progressive’ and did not place great value on culture, but acknowledged its undeniable presence in their lives. These caregivers appreciated the value that culture brought to their experiences, but were fluid in their preservation of South Asian culture in their lives. One of the male caregivers, who had lived in Canada for several years, felt that as immigrants, “we should amalgamate into [Canadian culture]” (Participant 2, Indian Husband). He was passionate about the importance of adapting Canadian culture and values as an immigrant. Nevertheless, culture had some impact and influence on the overall experience, especially within the following aspects of the experience: (a) “It’s my duty”: the decision to be a caregiver; (b) “I’m not understanding many things because of my language barrier”: the influence of language on the palliative experience; (c) “it’s important to keep them at home in our culture”: living and dying in the right place; (d) “they never told her she was dying just to keep her hope alive”: protecting each other; (e) “he would not allow any outside help”: stigma against paid caregiver roles and; (f) “for his satisfaction, we made the food”: cultural role of food in the palliative approach.

“It’s My Duty”: The Decision to be a Caregiver

Cultural values and perspectives influenced the caregivers’ motivation for taking on the caregiving role. A female who looked after her mother described her sense of loyalty to the culture as the reason she felt a sense of duty and obligation towards taking on the role of a caregiver:

> It’s really important, because our parents are important. We have to take care of our parents in their last days of life the same way they took care of us. That’s their expectation. At the same time, we don’t have time. Work is important. But in our culture it’s important. It’s our duty to do that for them. That’s part of our culture, it’s our duty. The culture here is different, but because they came from back home [Sri Lanka], they still expect us to take care of them. It’s their last wishes. So we need to fulfil their wishes, and that’s what will make them happy. (Participant 11, Sri Lankan Daughter)

This daughter held a strong cultural belief that it was important to care for the elderly in the EOL. However, she struggled with upholding her duty to her elderly mother while maintaining her other responsibilities. In particular, she felt that the difference in lifestyle and culture in makes it more challenging to care for elderly family members in Canada than if she had been living in Sri Lanka. Another caregiver, who was a daughter-in-law, expressed that “whether [I] want to do it or not, it’s [my] duty. Considered [my] duty” (Participant 7, Indian Daughter-in-Law). Thus, caregivers felt that they had an obligation to care for their family members in the EOL, regardless of availability, preference or other factors that may usually impact this decision. As such, culture was a clear driving force behind many caregivers' rationales for taking on the caregiver role. While there were practical challenges in fulfilling this duty, the sense of duty and obligation overshadowed these challenges. As one caregiver explained, "Sometimes it was too much for me. It's hard, but it's my mom right, so I have to do [it]" (Participant 1, Sri Lankan Daughter). Despite feeling overwhelmed with the role of caregiving, this caregiver felt that she had a responsibility to fulfil the role.

A few caregivers reinforced the idea that the eldest sibling or the male of the family should take on the responsibilities of caregiving and looking after the family. Despite this cultural idea, extraneous circumstances sometimes forced non-male individuals into the caregiving role, as was the case for a daughter who cared for her father:

> Yeah [the] son is [more] responsible than daughter. If the daughter wants she can do it, but the son is more responsible. But in my case, my brothers went [to] study in Bangladesh and now they are studying over there in [their] final year [of] Bachelor of Medicine, Bachelor of Surgery. I was the one [who had to step in]. I was with my mom and my dad. I [had] to be there at that time. So I went [to Nepal]. (Participant 10, Nepalese Daughter)

However, once again caregivers recognized that upholding these cultural obligations was not without its challenges:

> We are willing to [be a caregiver]. But, yes you are right, it might be socially enforced or if you are the son-in-law or if you are the daughter-in-law, you will take care of them and you can do it at home. But when you actually see the

> conditions people are in, the physical or mental challenges [they] have, it's really tough. (Participant 3, Indian Daughter-in-Law)

Caregivers recognized that there were socio-cultural expectations that led them to be caregivers, regardless of their willingness to take on the role. It was apparent that cultural perspectives, experiences, values and expectations had different levels of influence on caregivers' sense of duty towards their family members and their decisions to take on the role. However, the degree to which these cultural aspects influenced caregivers' decisions and experiences varied between individuals.

"I'm not understanding many things because of my language barrier": The Influence of Language on the Palliative Experience

English was a second language for all except one caregiver. Many of these caregivers expressed challenges they faced with language barriers that prevented them from understanding the circumstances and from communicating effectively with the health care team at the EOL. A caregiver with a medical background acknowledged the challenges presented by poor English proficiency: "Yeah there is a language barrier. I can speak and understand [English], but of course [I am] not as comfortable [as I would be] in my native language" (Participant 6, Pakistani Husband). When this caregiver was asked to clarify whether his wife had received a palliative approach to care, he replied, "Maybe [the doctor] told me that time…the thing is, I am not understanding many things, because of my language barrier" (Participant 6, Pakistani Husband). While this caregiver had medical experience and an understanding of the palliative approach, his language barrier prevented him from being able to communicate clearly to HCPs about his wife's condition, thereby hindering his ability to care for his wife.

Another caregiver expressed similar challenges with language barriers, hindering her ability to perform her duties as a caregiver: "It was difficult for [me], because it was easier to explain in Punjabi what to do. If something was misinterpreted or taken wrong, then [I have] to do all the work again" (Participant 7, Indian Daughter-in-Law). In an effort to overcome this challenge she requested a Punjabi speaking nurse. The idea of having HCPs that spoke the same language resonated with some caregivers. English was the first language for one caregiver, who described being heavily involved in the care of his father. Thus, he encountered very few instances where language was an issue. However, he acknowledged that efforts could have been made to make the experience more positive or inclusive for his mother, who had a significant language barrier:

> Yeah, if my mom ever told me to step aside and while I'm not there the PSW came, if the PSW spoke the same language as my mom it would comfort her, make it easier for her. Yeah, it's more comforting. (Participant 8, Pakistani Son)

Another caregiver provided evidence for how effective it was to have HCPs that spoke the same language: "We go [to] the doctor [who speaks] the same language – Tamil. My mom speaks Tamil too. So they talk to her and tell her [information]… Sometimes she complains about everything… [But] she speaks Tamil and the doctor speaks Tamil. So it worked" (Participant 1, Sri Lankan Daughter).

While not all caregivers encountered a language barrier, there were instances in which language helped to develop a connection and trust with the health care providers.

For instance, a caregiver described the benefits of having a Punjabi PSW who cared for her husband and assisted her in caregiving duties, despite the fact that no one in their family had a significant language barrier. She felt that the PSW "understood [us both] on another level" (Participant 4, Indian Wife) and described how the PSW would call her husband 'Uncleji', a respectful and endearing Hindi term used to refer to elders. One caregiver offered a different solution to overcome the language barrier: "Well my mom can't speak English. So if there were an emergency, it would be a good idea to have a Tamil phone line or emergency line you can call" (Participant 11, Sri Lankan Daughter). As a result of their experiences, caregivers reflected on how to bridge the gap between cultures by mitigating language barriers.

Caregivers recognized the impact language had on making a connection with HCPs, the quality of care, the sharing of information and the connection between cultures. Therefore, it is evident that language had a significant influence on the caregiving experience and was a substantial barrier to accessing support, expressing their concerns or needs, and communicating clearly with HCPs.

"It's important to keep them at home in our culture": Importance of Place In Living and Dying

Caregivers also placed importance on the place in which their family members resided while they were ill, their place of death, and to a lesser extent, their place of burial. Caregivers felt that it was important to honour the wishes of the family member and to ensure they were within the comforting presence of family:

> Oh it’s important [to keep them] at home, in our culture! My mom wishes that too. [She said] ‘I have to die in this home, in this house. I don’t want to go anywhere’. She said she doesn’t want to die in a strange place. So her wish came true. (Participant 1, Sri Lankan Daughter)

For some caregivers, a good death could only be achieved at home, despite the challenges it brought. Unfortunately, for these caregivers moving their family members into a LTC home was an inappropriate alternative, as this was viewed as “taboo” in their culture. One caregiver felt that putting his mother in a LTC home was not the best option for him or his mother:

> The bottom line is we don’t want to leave her in a place and just forget about her. We always want to be with her. And same with her, she doesn’t want to be away from home. So that’s the main thing. (Participant 9, Sri Lankan Son)

For this caregiver, being able to continue to care for his mother at home and ensuring that family and friends always surrounded her defined a good death. Thus, he felt that this could not be achieved if his mother was moved to a long-term care home.

Several other caregivers shared this negative perception of the long-term care home and viewed it as a symbol of abandonment. Another caregiver described wanting to take her mother home from the hospital, but did not have the right amenities and resources to care for her mother at home in the EOL. When given the choice of moving her mother to a hospice or LTC home versus having her remain in the hospital, she chose to keep her mother in the hospital. She felt a sense of abandonment associated with placing her mother in a hospice, stating that “it would feel sad leaving her there, like you stopped caring about them" (Participant 11, Sri Lankan Daughter). When reflecting on her experience, she also expressed her satisfaction with her decision to also choose against a LTC home:

> I'm happy that we didn't put her in nursing home in the end of her life and she was with us till the end. She wouldn't have liked that and I would have felt bad. But I'm happy that she was with me till the last minute and happy till the end. (Participant 11, Sri Lankan Daughter).

For this caregiver and her brothers, staying actively involved in caring for their mother was the most important priority, regardless of how challenging it became.

Another caregiver felt similarly about her mother-in-law's circumstances, even after having heard about the benefits of the hospice:

> …the hospice they have the facilities. But…I want [it] to feel like home. I don't want [it] to feel like [they are] in the dead zone. I know [the hospices] are peaceful. They are doing things and saying things [that help], but I want [her] to enjoy with my family. (Participant 3, Indian Daughter-in-Law)

This sceptical perception of the hospice resonated with another caregiver who refrained from moving her mother-in-law to a hospice because "[we] did not want her to feel that she was going to die. In hospice, [we] thought that she would realize [her fate] and that she might, you know, die earlier" (Participant 7, Indian Daughter-in-Law). Keeping their family member at home was the most beneficial option, as one caregiver explained:

> The help that I can give [my husband] here, no one else can do it. No one else can do it, because if he asks for something, I will do [it] straight away. If he was in nursing home, he has to wait for that [help]. (Participant 4, Indian Wife)

Overall, there was a general consensus that keeping their family members at home was the best option. One female caregiver noted that there were factors that affected and validated the decision to continue to care for their family members at home:

> Yeah, I would say for the elderly women and immigrants, culture, language and education are the issues affecting whether we put them in the nursing home or keep them at home. And it's very hard to find people in the same language.
>
> (Participant 1, Sri Lankan Daughter)

Thus, caregivers felt there were several benefits to keeping their family member at home.

Few caregivers detailed the importance of the place of burial. However, one female caregiver expressed doing her best to fulfil the wishes of her mother-in-law:

> So I asked her what kind of rituals do you want me to follow? What are your wishes? She said 'I am gone, do whatever you feel like'. But to dad, she has said that take my ashes to India. And so we are going to take her ashes to India.
>
> (Participant 3, Indian Daughter-in-Law)

Caregivers appeared to place greater value on the location in which the family member resided while they were living with an illness and their place of death, as opposed to their place of burial.

“They never told her she was dying just to keep her hope alive”: Protecting Each Other

Caregivers were focused on ensuring that their family members lived happily and had a good death. A good death was determined by the physical and mental well-being of their family members, which was supported by keeping their “hope alive”. There was a shared notion that keeping information from the family member about their illness would protect and preserve their sense of hope and encourage a more positive outlook. One caregiver explained that keeping information from his wife about her medical condition was better for her overall well-being:

> Because a person doesn’t know about what’s going on with her [body], so she’s still hopeful. She still has hope. And she is not thinking about herself that much, which could even worsen her condition. If she is thinking she has cancer, [then] she will be suffering from another problem, psychologically. (Participant 6, Pakistani Husband)

Caregivers shared the belief that providing details to their family members about their medical condition would foster negative feelings and atmosphere, thereby negatively impacting their mental condition. In turn, this negative mental state would worsen their physical well-being by causing them to “suffer more” or “deteriorate earlier”.

“He would not allow any outside help”: Stigma Against Paid Caregiver Roles

Caregivers expressed wanting to hire help or receive help from external sources, such as PSW and nurses. However, some caregivers noted that there were stigmas within their community associated with such roles, which may have affected their ability to hire someone or their openness to receiving external support. One caregiver shared what she believed to be her community's general perspective on professions, such as nursing or PSWs, which focus on providing physical care for clients:

> You know how [the PSWs are] bathing them, changing their diaper, and cleaning up … For example if someone from the same town comes, and they [will] say 'oh is this the job she's doing'… so they look down on the job. (Participant 1, Sri Lanka Daughter).

This caregiver sought to hire a PSW of the same culture who could speak the same language in order to ensure her mother could communicate her needs comfortably. Unfortunately, in this caregiver's experience, PSWs of the same culture were embarrassed to reveal their jobs to others in their South Asian community due to the associated stigma, preventing this caregiver from successfully hiring a PSW of the same culture.

Another caregiver offered her opinion on why this stigma existed in the South Asian community but may not be upheld as strongly among South Asians living in Canada:

> In my opinion, I think it's because in Sri Lanka there are more people, more family there, so you don't really need [the PSWs'] help. I think that's why [Sri Lankans] think like that. But here you definitely need [the PSWs]. Here life is so busy, so you can't stay at home and look after family. Here they're so important. Over there, I don't think you really need them. Usually a lot of people over there don't use nurses or PSWs. I don't know about nowadays, but when I was there,

> because we have aunts and uncles there, you don't need [the nurses or PSWs] so much. So that's why I think [the Sri Lankans] don't give them much importance. (Participant 11, Sri Lankan Daughter)

There have been other stigmas associated with such professions, as one female caregiver described, "they are not thinking good [things about the nurses] because the [female] nurses are talking with so many male people" (Participant 10, Nepalese Daughter). In this caregiver's community, it was considered taboo for males and females to work together or develop professional relationships. Thus, this stigma affected perceptions of nurses and the ability to seek their assistance. However, caregivers who have experienced or were aware of such stigmas acknowledged that there has been in a shift in culture weakening these stigmas in their respective home countries and within the Canadian-South Asian community.

"For his satisfaction, we made the food": Cultural Role of Food in the Palliative Approach

Food often played various roles throughout the experiences described by caregivers. While its significance sometimes went unrecognized by caregivers, it was apparent that it brought some value to the experience. For many caregivers, food served as a source of comfort to their family member who was ill. A female caregiver explained how making food for her mother-in-law had become a part of her role as a caregiver:

> [The LTC home staff] said okay you could bring [food], so she feels [at home]…She doesn't like to eat nursing home food. She preferred home food. So I

> had to make food for her and take it to the nursing home on my way to work. (Participant 1, Sri Lanka Daughter).

To this caregiver, making her mother-in-law's preferred or favourite foods would increase her comfort and well-being. It also was perceived to improve the overall quality of life of her mother-in-law.

The lack of food or the inability to eat was an indication that the individual was in the EOL. Some caregivers expressed having difficulty with this physical change and the inability to feed their family member in the EOL. One caregiver expressed the challenges of having to stop feeding his wife:

> Two weeks went like that and she was being fed, the IV was given. But the doctor came and said that…we can't do that anymore because her body is shutting down…That was a very tough, hard thing. I said I don't want to [stop]… I still have to feed her something. Then it was only, I think, two weeks after that she died. The doctor said, well the problem with [not stopping] is you can feed her, we can get the tube and all that, but the problem with that is she is not going to survive and she will suffer more. That was a very, very hard thing to do…I feel I'm killing her kind of thing. (Participant 2, Indian Husband)

The ability to eat and consume food was seen as a marker of one's well-being and influenced care decisions. One female caregiver who cared for her mother and father captured this idea clearly when she shared her strategy of using food to measure the costs and benefits of care decisions:

> In the last days, at least if he can get up and eat the food, even [he is] not walking to the washroom or those things, at least if can he eat the food...he will eat whatever he wants. Otherwise there is no point to keep them longer and making them suffer. (Participant 5, Sri Lankan Daughter)

For this daughter, her father's ability to consume and enjoy food was a measure of his well-being and quality of life. The inability to do so indicated poor quality of life and that her father was suffering.

Food also played a role in relationships and connections between caregivers and their family members. It was viewed as a display of love, care and connection, as explained by one caregiver's recall of her connection with her mother-in-law through cooking:

> She was very fond of eating Indian food especially [what] we cooked at home everyday. And [the family] is so accustomed to what we cook [at home, that] now they don't find the restaurant food that appealing. What we have at home we would like to eat that. So [my mother-in-law] taught me cooking. I know how to cook but I didn't have any interest in cooking. But since I came in this house, she taught me how to polish the way you cook food. So I took it in like a sponge, absorbed it, whatever recipes [she gave]. (Participant 3, Indian Daughter-in-Law)

This caregiver found it important to build a connection with her mother-in-law and to carry on her legacy through cooking. As such, cooking and sharing recipes became an important part of her role as a caregiver in the EOL. She later explained how extended family members expressed their support through food, following the death of her mother-in-law:

> They made sure they provided food [for us]. And up to the day of the funeral, the food was coming. Everyday they had their own duties written on the calendar. Like breakfast, who is bringing breakfast, who is bringing lunch and dinner. (Participant 3, Indian Daughter-in-Law)

This caregiver felt comforted and supported during bereavement when her family members offered food as a gesture of support. Therefore, food was often used to show affection and build connection among family members.

Only one caregiver described the role of food in rituals that are done for the dead:

> We are offering food, once at night. Before my brother [eats], we have to offer food to the dead. We have to take some food and put [it] somewhere where nothing is going on, like some place [quiet] and we have to put water in glass and one plate and we have to put food over there. So first we have to take out the food for the dead people and then we have to eat. (Participant 10, Nepalese Daughter)

This caregiver described the ritual of offering food to the dead prior to eating. This ritual was carried out by her brother and was important in honouring their late father.

It was evident that food had varying roles in caregivers' experiences. Its role, importance and significance varied between caregivers and were dependent upon the stage of the experience. In addition, food often marked significant moments throughout the experience. Despite its varying presence in the caregivers' experiences, the power of its presence is irrefutable.

The Challenges of Being a Caregiver

While participants wanted to care for their family members, they faced several challenges throughout their experience. These challenges are described in the following categories: (a) “I do what I can. It’s hard sometimes”: finding a balance; (b) “I could have done more”: the pressure to be a good caregiver and; (c)“we didn’t have any clue”: understanding the experience.

“I do what I can. It’s hard sometimes”: Finding a Balance

In adopting the new role of the caregiver, all participants described the ways in which their day-to-day lives had changed and the challenges it brought in trying balance different responsibilities. Caregivers described new ‘added responsibilities’ such as a taking their family members to medical appointments, getting groceries, cleaning, cooking, massaging, bathing, and essentially “doing everything”. One caregiver said that “in the beginning it was very hard to keep track” (Participant 4, Indian Wife) of the medical aspects of care and described feeling overwhelmed with these responsibilities. In response to this particular challenge she said, “I made myself a…diary. I used to write everything there. You know, [like] we went for CT scan, we went for treatment, what kind of medicine he is taking. So I was keeping tracking” (Participant 4, Indian Wife).

Caregiver responsibilities grew as their family members approached the EOL and required more attention. One young male caregiver creatively described the experience of caring for his father as going from a “part-time job to a full-time job” (Participant 8, Pakistani Son). Similarly, another elderly female caregiver felt that her husband was her “first priority” above anything (Participant 4, Indian Wife), citing her duty to care for him as his wife. Trying to balance their own responsibilities, such as work, family, and children, alongside their newfound responsibilities as caregivers proved to be a challenging experience, as described by this daughter-in-law:

> So [I] had to look after her kids and after her husband. This is a cultural thing. And then [there were] added responsibilities, [like] personal care. But the other thing was people would come and go to see the patient almost all day. So [I] had to take care of those guests also. (Participant 7, Pakistani Daughter-in-Law)

For this caregiver, the cultural expectation that she care for her family members and demonstrate hospitality to her guests, in addition to caring for her mother-in-law, proved to be a stressful and challenging experience.

Similarly, for another caregiver, caring for her mother and mother-in-law at the same time magnified the challenge of balancing all her responsibilities:

> …sometimes, you know [my mother and mother-in-law] expect more. You know sometimes I lost my patience [because] they expect more, but I already have so many things on my plate. Sometimes I think I have to transfer one of them somewhere because I had to get a break. But I couldn't. (Participant 1, Sri Lankan Daughter)

This caregiver was overwhelmed by the responsibilities of having to care for her mother, mother-in-law, as well as her family. While she wanted to seek out professional support or move her mother or mother-in-law into a LTC home for respite care, she was unable to do so due to cultural taboos around LTC homes and the socio-cultural expectations that she fulfil her role as a caregiver. Although caregivers recognized that "you need someone's help. It's also not something one person can handle on their own" (Participant 11, Sri Lankan Daughter), they appeared to accept the circumstances and made the best of the situation. Overall, caregivers expressed working hard to fulfil their responsibilities to the best of their abilities, demonstrating resiliency.

"I could have done more": The Pressure to be a Good Caregiver

Caregivers also described feeling pressure from external sources or putting pressure on themselves to fulfil their role successfully. One caregiver explained why she refrained from asking for help while caring for her husband stating, "Because I don't want to bother anyone. Whatever I can do myself, I want to do it myself. I will call someone if I can't do it myself or I will wait till the morning" (Participant 4, Indian Wife). Another caregiver expressed feelings of inadequacy when reflecting on his role, when he said, "To be honest, even though everyone tells me I did as much as I could, I did more than anyone probably would have, I still feel like I could have done more" (Participant 8, Pakistani Son).

In addition to putting pressure on themselves, caregivers also expressed facing criticism and pressure from family members for failing to fulfil role expectations or making care decisions with which extended family members disagreed:

> Yeah I took care of my mom for eight years by myself. And then for one and a half months I put her in the nursing home because I got sick. And you know in our culture we don't put them in the nursing home. Then the problem started. My brothers were so upset because [they said] I shouldn't put her in the nursing home.

> But at the same time they don't want to take care [of her]. (Participant 1, Sri Lankan Daughter)

Due to the cultural expectation to care for family members at home and the taboos associated with moving family members into the LTC home, this caregiver faced conflict with her family members for her decision. This caregiver later moved her mother back home. While she began to receive more assistance from her family members, she remained the primary caregiver and decision-maker, and still held the weight of her responsibilities. Another caregiver explained that "she would have to take the blame" (Participant 7, Indian Daughter-in-Law) if she did not interpret or explain her mother-in-law's condition or medical aspects of care accurately.

In one instance, a caregiver described feeling pressure from extended family members to conduct cultural rituals following her father's death. In particular, she was expected to feed a large group of friends and family, as it was a cultural expectation following the death of an individual. However, she felt that the level of economic burden this placed on her family went unacknowledged:

> Like some [people were] forcing [us, saying that] 'you have to do it like this'…Even in the case of my father, some people were saying 'you have to do like this [cultural rituals and traditions] in his name'. But our economic condition [did not allow this]. So we can't offer that type of stuff. [For example] after thirteen days we have to feed so many people. In thirteen days there were thousands of people [that came] and you have to feed them. We have to make food and [hire] catering for these things. And for this amount [of people] we paid

> $1000 for the charge. Just for the catering charge we paid $1000, Canadian dollar. (Participant 10, Nepalese Daughter)

While this caregiver felt her culture was important and wanted to uphold cultural traditions, she felt that her family members and her community were pressuring her to make certain decisions with little regard for the well-being of herself and her family.

Despite the intense internal and external pressures, caregivers demonstrated resilience, and endured criticism to meet expectations. As an example of their resiliency, a caregiver described how she witnessed her husband overcome personal challenges to fulfil his responsibilities as a caregiver to his mother:

> And my husband is the type of person who can't see blood. He faints, he can't see somebody going through pain – he faints. And he was injecting injections in her tubes. And I was saying you have turned out brave, more than I expected. I was giving [my mother-in-law] injections, I was giving her blood thinners in her stomach, but he eventually took over, and he has to do those duties in the night. So, it is not easy caring for each other so much that you strain yourself. It is too much. (Participant 3, Indian Daughter-in-Law)

As such, the tendency of families to be involved in care decisions within South Asian culture and the expectations placed upon caregivers by their family members can be stressful and burdensome for caregivers. However, caregivers demonstrated resiliency in dealing with this additional pressure.

“We didn’t have any clue”: Understanding the Palliative Experience

Many of the caregivers’ family members received a palliative approach to care and EOL care. However, most of these caregivers expressed a lack of understanding of the meaning and purpose of a palliative approach, as it was not discussed within their community. For one caregiver, this was a significant knowledge gap, which she took the initiative to overcome on her own:

> At the end she was in palliative care. We didn’t have any clue what that was. So the doctor said because her breast cancer turned to colon cancer, spreading through there, that now we have to stop all the medication, [and] she is going to be in palliative care. So we asked her, what is this? I don’t get it? So I Googled it. (Participant 1, Sri Lankan Daughter)

She later explained that the information she gathered about palliative care on the Internet did not reflect her experiences, as her expectations of care were not met: “So [the Internet] said, oh the professional will work with her, and [she will] get all this support. And that [the] family will get support too. But I didn’t get much and within a day or two she passed away” (Participant 1, Sri Lankan Daughter).

Other caregivers had heard the term ‘palliative’, but still did not grasp its meaning or purpose: “Before I just knew there is palliative care, but I don’t know what it was exactly. I just know that there is a thing palliative care, that’s it” (Participant 5, Sri Lankan Daughter). For some caregivers, this lack of understanding arose from language barriers, while for others it was attributed to unawareness of the term.

Coping with the Challenges of Caregiving

The role of the caregiver is a difficult position and the overall experience was described as stressful and emotional. During such a difficult time, these caregivers relied on various activities and actions to help them move forward through the experience and to maintain their mental health. Caregivers described various coping methods: "you go towards God and he makes it all easier: finding strength in spirituality; (b) "it was hard for me, but I blindfolded myself": blocking it out; (c) "time does heal things": coming to terms with the experience and; (d) "turn the bad things into positive things": maintaining a positive attitude.

" You go towards God and he makes it all easier": Finding Strength in Spirituality

Religion and spirituality seemed to play an important role in many of the caregivers' experiences. For many caregivers, religion was tied with culture as they complimented each other with regards to customs, traditions and values. One caregiver described her firm belief in God in reference to her experience, "I used to just pray myself. When it's a bad time I pray. I say whatever God you will give it to me, I will accept it" (Participant 4, Indian Wife). While some caregivers expressed having a pre-established firm belief in God, others expressed having developed a newfound faith in religion as a result of their experience. One elderly caregiver explained the impact the experience of caring for his wife had on his view of God and life:

> Now I see that God maybe…maybe He's the one who makes everything [happen]. That's what I started believing. Before, I wasn't into [religion] that much. But

> then I listen to [religion] now and try to understand what life is all about and how it works. He's [God] the one who does anything. (Participant 2, Indian Husband)

Another young caregiver had a similar experience, in which he came to appreciate the power of religion in his life:

> I'm not going to say that I'm a full on religious guy, but I still so pray sometimes. Every time something bad happens, my mom tells me read this certain prayer, at this time, read this one at that time. So like, I guess it's like a placebo effect at the same time. They're telling you that it's going to make you feel better, [and] it actually does make you feel better. (Participant 8, Pakistani Son).

This caregiver later elaborated on his perspective and described the act of prayer as a source of hope and comfort during such a difficult time. Caregivers also turned to religion and spirituality to make sense of their unfortunate circumstances and to assist them in coming to terms with the fate of their family member. For instance, caregivers often felt it was God's will or used prayer to help cope with the experience.

"It was hard for me, but I blindfolded myself": Blocking It Out

As a coping mechanism, some caregivers explained that they tried to 'detach' themselves from the situation or 'block' out the reality of the situation in order to move forward in the experience. A caregiver described this idea in reference to his experience of caring for his late wife:

> I couldn't even see that [she was dying]. It was a very hard time… for 2 -3 days it was very, very hard to see. Only the thing I [could do is] just block [it out]. Whatever God did that time, it blocked everything. I couldn't even feel

> anything…and in the last moment I couldn't even see that she was gone.
> (Participant 2, Indian Husband)

This husband described finding it so hard to witness his wife's condition deteriorate and found it challenging to acknowledge that she was dying. To cope with the fact that she was dying, he did his best to ignore anything in the situation that was causing him emotional pain. Another caregiver shared a similar idea and described 'detaching' herself in order to give herself the mental capacity and strength to carry out her role as a caregiver for her mother-in-law and her family:

> Certain people have ability to detach themselves in certain conditions and I know if I want to detach myself, I can detach. It's my ability. If I can bond with somebody, then I can detach myself too. This is how I work. If I am not able to detach myself from mom's condition, I won't be able to take care of you guys or the family or running the household or doing anything. There is a boundary set for me, [and only] so much I can do. Then I have to draw a line for myself.
> (Participant 3, Indian Daughter-in-Law)

Caregivers also described going through the motions of caregiving but not taking the time to comprehend the situation: "I never thought about it…I never look for results. I just keep doing my duties" (Participant 4, Indian Wife).

They often tried to redirect their focus onto other leisure activities or hobbies in order to cope with the stress and difficulty of the situation. Talking to family and friends was a popular choice of activity and served as an effective coping mechanism for many caregivers. However, one caregiver described feeling appreciative of having supportive friends but apprehensive about burdening his friends with his emotions:

> That's why I usually go outside, go for a walk, or talk to my friends, but I don't want to keep giving out depressing vibes. Like 'hey you want to chill, I got to talk to you about stuff?' and do that for like a week straight, I'm pretty sure my friend wouldn't want to chill with me at that point, you know. (Participant 8, Pakistani Son)

Engaging in hobbies or leisure activities that served as distractions was also a popular method of coping. One caregiver was enthusiastic about creating a 'personal zone' where she was able to remove herself from the experience for a short period of time:

> I have to bring my bag. Upstairs the room is different. But when I come down, I make the change. Anything scribbling, colouring I kept around. So music, my phone, news, certain idiotic things, anything related to style. Nothing with cancer. That was my motive. (Participant 3, Indian Daughter-in-Law)

Other activities described by caregivers include going to the gym, yoga, going for walks, reading, listening to music, cooking, cleaning, taking care of children or even working. One caregiver summed up the impact of "keeping busy" when he said, "As soon as I started working, I got busy in the work. And when I got busy, then I got better" (Participant 6, Pakistani Husband).

"Time does heal things": Coming to Terms with the Experience

Caregivers expressed some difficulty with accepting the circumstances of their family members. In reflecting on their experience, some caregivers felt that the experience could have been avoided or delayed. One female caregiver captured this idea when she spoke about her father, “I think, for me, the frustrating thing is, it could have been avoided. Had the doctor just given him a colonoscopy…I just think it could have been avoided” (Participant 4, Indian Wife). Other caregivers “blamed” HCPs and identified HCPs’ “negligence” as contributors to the illness or death of their family member.

While caregivers understood that their family member was ill and death was imminent, it was difficult to fully and internally accept this. One male caregiver described witnessing changes in his wife’s breathing, but did not recognize this as a sign of death. Rather, he was hopeful that it was a sign of improvement. He said, “But I didn’t think the other way, that ‘hey maybe she’s not improving, that it’s time to go’ kind of thing” (Participant 2, Indian Husband). He attributed this lack of knowledge and awareness to language barriers and the failure of HCPs to provide clear information regarding his wife’s circumstances. This caregiver later expressed the difficulty of coming to terms with his wife’s death, acknowledging that God “somehow he took her away” and that he is still “getting over that” (Participant 2, Indian Husband).

It was apparent that caregivers continued to reflect deeply on their experiences and question the course of events and its impact on the outcome of the experience. However, they also recognize that “you cannot live in the past. Whatever happened, happened” (Participant 4, Indian Wife) and that “time does heal things” (Participant 8, Pakistani Son). Therefore, caregivers were “slowly accepting” the death of their family member and coming to terms with their experience over time, while reflecting on the challenges they faced.

“Turn the bad things into positive things”: Maintaining a Positive Attitude

The aforementioned coping mechanisms and actions were an effort to stay positive throughout the experience and cultivate a positive atmosphere. Caregivers made a conscious effort to direct their focus on staying positive. One caregiver shared the philosophy that she and her family lived by while caring for her mother-in-law: “We try to turn the bad things into positive things and we are proud of that and we will do that more” (Participant 3, Indian Daughter-in-Law). Another caregiver echoed this philosophy when he said, “Well only thing [is] you have to think a little bit positive. I think that’s the only one thing...I was feeling positive all the time, even up to the last moment” (Participant 2, Indian Husband). Upon reflection, this caregiver credited his focus on keeping a positive attitude with getting through the experience and helping him cope with the death of his wife.

Maintaining a positive attitude was seen as important to keep oneself motivated to fulfil the role of the caregiver, as well as other roles in their lives. This was especially highlighted in one caregiver’s account of events:

> Well we just, it’s kind of [like] I tell my sister and wife, we have to look after the other people as well, our family, our kids and stuff. So we cannot go down just thinking about mom. We also have to have the strength to take care of the other stuff. That’s the main thing we all keep saying. It’s not that we’re not worried

> about what's going on. We just want to make things balanced. (Participant 9, Sri Lankan Son)

As such, in addition to maintaining a positive attitude and fulfilling caregiver duties, it was important to maintain a balanced lifestyle. For these caregivers, there was a strong internal source of motivation. However, for other caregivers the source of motivation was an external source, usually a family member or friend. One caregiver explained the impact his father's words had on his ability to cope with the stress of the situation:

> 'Spend the time trying to be happy. Don't spend the time with negative vibes. Always try to keep a positive vibe'. He was trying to motivate me to continue on with my life, because obviously at a time of death, it gets really hard for some people, with like depression, anxiety, possible suicidal thoughts and stuff like that. But I guess, hearing that from my dad in that time, and knowing what's going to happen, it's more reassuring and more comforting. And seeing my mom stay strong, it all together it kind of helped me stay strong too. Keep my thoughts normal, no negative vibes and stuff like that. (Participant 8, Pakistani Son)

Based on caregivers' recount of experiences, it was evident that they strived to demonstrate emotional strength throughout their experience and in bereavement in order to personally cope with the experience and help their family members cope.

"You need someone's help": Caregivers Receiving Support

A prominent aspect of the experience was receiving support from various individuals. Some caregivers also described obtaining bereavement support from external sources, such as bereavement support groups. In particular caregivers received support from three different sources: (a) “the family helped a lot”: relying on family and friends; (b) “we appreciate what they did”: receiving health care provider support and; (c) “it’s not really me, to be honest”: perceptions of formal bereavement support.

“The family helped a lot”: Relying on Family and Friends

Family and friends were a primary source of support for the caregiver throughout their experience and in bereavement. One caregiver described how she and her family members supported each other when caring for her terminally ill mother-in-law:

> I talk with my husband. We have given support for each other. Sometimes, some days he cries, I listen. Sometimes I cry, he listens. Sometimes we both cry and our brother-in-law listens. Some days he cries and we both listen. So there have been lot of times dealing with emotions, trying to understand each other. And I think this where we, actually my husband and me, we came much more closer. (Participant 3, Indian Daughter-in-Law)

The involvement of family and friends in sharing the responsibilities of caregiving “made life a lot easier” (Participant 2, Indian Husband), as stated by one elderly caregiver, who was referring to the support he received from his daughters.

Examples of support provided by family members include financial assistance, helping with day-to-day activities, moral support and emotional support. Families that were not physically present were still able to provide moral or emotional support by talking on the phone. Thus, the presence of family was highly valued, as caregivers expressed a deep sense of gratitude and appreciation for the support offered by family members.

Caregivers also described feeling supported by other people in their lives, such as friends or co-workers, who often offered moral support:

> Yeah I couldn’t even work. When I was at work, I would start to cry, and my co-workers used to try to make me feel better. Everyone would say [my mother’s] time is almost done; you have to take care of her. You are her child and you have to be a strong person. Everyone was giving me advice. (Participant 11, Sri Lankan Daughter)

Another caregiver sought the help and expertise of her co-workers to help her care for her mother or answer questions:

> Luckily at the early years centre I work with nurses, so I talk to them about how to do things. Like my mom had uncontrollable bladder so I asked them how to deal with that, because I don’t have any nursing background or a PSW background. So they helped me a lot. (Participant 1, Sri Lankan Daughter)

In contrast, one male caregiver expressed feeling ‘lonely’ because his family was in Pakistan and unable to obtain a visa. While he was offered the support of his friends and in-laws, he felt that it was insufficient:

> I don’t have any family member out here from my background. But my friends were helping me. They were with me for the whole week. And they were telling me that if you need something, I’m here. And we’ll do anything you want us to do, we can do that for you. But the thing is everybody was working. And they cannot do anything during work time. So eventually you have to do everything by yourself. But they can do some things in the evening when they are not working.

> Mostly, they were helpful and everything, but they couldn't do lots of things for me. (Participant 6, Pakistani Husband)

Another female caregiver expressed a total lack of support from her extended family and was limited with whom she could rely on for emotional support. She explained, "[I] could at least cry with [my] sister. But [I] tried not to do that in front of anyone else, because…they might take it as pretend", referring to her strained relationships with her in-laws (Participant 7, Indian Daughter-in-Law). While most caregivers felt supported by their family and friends, some caregivers experienced challenges in seeking or receiving appropriate support. Regardless, the presence of family and friends in their lives during such a difficult time, or lack thereof, impacted the experience deeply, signifying the value it held among caregivers.

"We appreciate what they did": Health Care Provider Support

Caregivers had varying views on the support they received from HCPs, such as physicians, nurses, PSWs, social workers and volunteers. Each profession had a different role in the care:

> The doctor and nurse, they helped with the medicine and all the main medical reasons and stuff. The PSWs would help with the cleaning, the room, cleaning him, showering him, changing his clothes, changing the bed sheets, all that stuff. Yeah, so really helpful. (Participant 8, Pakistani Son)

Two participants used the phrase "doctors are next to God" relaying the level of trust they had in the doctors' decisions and expertise, with one participate stating "whatever they say we believe" (Participant 11, Sri Lankan Daughter). However, these caregivers developed a newfound sense of betrayal and distrust in the doctors following the events of their experience, thus weakening their belief that 'doctors are next to God'. One caregiver explained why her attitude changed:

> Some of the doctors they will explain everything. But some of them really don't. They think oh if we explain, these people are not going to get [it]. Most of the doctors think that if they explain everything these people will get upset and they might yell at us. That's why they don't explain. That's the reason. Because some of the people [patients] who really don't know [or understand], they might get upset. But we know, but [the doctors] don't want to explain because maybe they had some bad experience or something [dealing with other patients]. That's what I think. And even for the doctors also it's really hard to tell [us], they can't tell [us] right away. Especially for my dad the doctor doesn't want to tell us most of [information]. (Participant 5, Sri Lankan Daughter)

This caregiver felt that the doctors were hesitating to provide clear information because they feared that their patients would become upset with the doctors or blame the doctors. She believed that doctors viewed people such as herself as unknowledgeable or unable to understand complex health issues and information. Thus, she believed that doctors felt their efforts to communicate with South Asian patients and families would be in vain. In her experience, doctors were unwilling to take the time to communicate clearly and provide detailed information about her father and mothers' health condition.

The lack of clear communication between physician and client was an area of concern for a few caregivers, who felt that they were not receiving sufficient information from the health care team and not offered enough support. In contrast, other caregivers felt well-informed and satisfied with the care delivered by physicians. One caregiver said, “The doctor was nice. She listened to [my father]. Like if he was in pain, she actually sat and listened” (Participant 4, Indian Wife).

Similar to the experience with physicians, the experience with nurses varied greatly. For one caregiver, she felt that the “nurses provide a big help. This is happening, how to deal with it” (Participant 3, Indian Daughter-in-Law). This caregiver described making special connections with three nurses, stating that she “trusted them” and was “able to talk to them” (Participant 3, Indian Daughter-in-Law). Other caregivers appreciated the nurses but they expressed some criticisms:

> This German lady, she was a good nurse. She always did everything for my mom on time and asked what she needed. She was a good nurse. But I do have one criticism. When we admitted my mom to the hospital in the beginning, they gave her really good care. But as time went, it felt like the quality of the care was decreasing. It was the same care, but less quality. (Participant 11, Sri Lankan Daughter)

Almost all of the caregivers described having PSWs involved in the care of their family members. These caregivers were content with the care provided by PSWs. In a few cases, caregivers did not recognize the value of PSWs until after their experience working with them:

> So even at the beginning, the PSWs they offered and we said no we don’t want, we can manage on our own. But after we started getting the PSW that’s when we

> knew that it does really make a difference. We really made use of it afterwards. (Participant 9, Sri Lankan Son)

Some caregivers felt that the PSW involved in the care demonstrated exceptional care and concern. In one instance, the PSW "learned a lot of Tamil" (Participant 1, Sri Lankan Daughter) in order to communicate with the caregiver's ill mother, who was unable to speak English. In reflecting on the PSW's involvement, this caregiver said, "You know I feel the difference when it was only myself working with her, and having another person come taking care of her. It was a huge difference" (Participant 1, Sri Lankan Daughter). Although some caregivers were initially apprehensive about the involvement of PSWs, they later praised their value. Another female caregiver felt that the PSW they had hired provided extraordinary care, "She worked hard to be patient, and pray… she did a great job. Even we couldn't look after her like that" (Participant 11, Sri Lankan Daughter).

However, similar to the experiences with doctors and nurses, caregivers had varying experiences and opinions about the involvement of PSWs. One caregiver was upset with the unpredictable timing of nurses or PSWs visiting the home and felt it was "annoying". Another caregiver described a situation in which the PSW looking after her mother-in-law in the LTC home demonstrated unprofessionalism, likening the behaviour to abuse and negligence.

"It's not really for me, to be honest": Perceptions of Formal Bereavement Support

Some caregivers received bereavement support from external sources, outside of family, friends or HCPs. They expressed varying views on the benefits and availability of the external bereavement support services. Some caregivers felt that external bereavement supports (such as counselling and support groups) were unnecessary, as they were offered sufficient support through family and friends:

> Since we have our family, we don't need that. Those people who are alone [might need it]. But even if I'm living alone, everyone [in my family] is always calling me to check on me, because they know that I've probably been affected by her death the most. (Participant 11, Sri Lankan Daughter)

In contrast one caregiver felt that she would have benefited from attending a support group, but did not have the time:

> Actually the [support group is] going on every Saturday. Saturday I have my son and daughter at home. My husband, he is working on weekends. He is not working on weekdays because he didn't found any job on week days regularly. So he didn't get any job, that's why I have to take care of [the children] on weekend. So [since] I have to be with [the children], I can't go over there [to the support group]. (Participant 10, Nepalese Daughter)

Although some caregivers were aware of the support groups and expressed interest in them, there were contextual factors and barriers, such as time, looking after children or conflict with other responsibilities that prevented them from attending. Only two caregivers took advantage of bereavement supports or resources. The first caregiver had learned of a bereavement support group through his children. He had mixed feelings about the bereavement support group he attended:

> During [the support group], I learned a lot. It did help some, but it didn't help much really. But…it's the time. Time is the one that makes it… and the way you react after that. (Participant 2, Indian Husband)

While this caregiver felt there was some benefit to the support group, he felt that his grief could only be overcome with time. As such, he was not very enthusiastic about the support group and the potential benefits it provided.

The second caregiver was much more enthusiastic about the availability of these resources and actively sought out these resources herself. She applied high value to these resources and felt that people should take more advantage of their availability, as well as take the initiative to seek out these resources:

> We say that we are in a country where everything is available. You are fool if you don't know the availability of services. Help and everything is available. If you don't avail it, then it's your own fault. You have to just open your eyes and ask the questions. (Participant 3, Indian Daughter-in-Law)

Although this caregiver was aware of the resources and felt strongly about utilizing them, most of the caregivers did not actively seek out bereavement support resources or were unaware of their availability. Furthermore, among those who did become aware of the resources, it was rare that they sought out these resources themselves. In general, many of these caregivers recognized the potential value of these resources but debated their personal benefit.

Summary of Findings

After exploring the experiences of bereaved South Asian family caregivers, five themes were identified to describe their experiences. Underlying cultural values and perceptions shaped their experiences in various manners. The influence of culture was strong in some experiences and limited in others. In some cases, it was apparent that cultural values and perceptions were influencing the experience, unbeknownst to the individual. All the participants described feeling some sense of duty or obligation to take on the role of a caregiver. For some caregivers this sense of duty was strongly motivated by cultural values, while for others cultural values played a smaller role. The place in which caregivers' family members remained while ill and at the time of death was also important. Keeping their family member at home and respecting their wishes regarding their place of death was important to caregivers. For some caregivers, moving their family member into a LTC home was a cultural taboo. Caregivers also refrained from sharing medical details with their dying family members, in an effort to maintain a positive attitude. Culturally, some participants expressed that there were some stigmas associated with formal caregivers, such as PSWs. While all participants did not echo this idea, it was apparent that this stigma influenced perceptions of external support services. Finally, food had various roles and significance for every individual, with the most significant commonality being that it was a source of comfort and served as a marker for one's well-being.

Caregivers experienced several challenges throughout their experience. All of them were faced with the task to trying to balance other aspects of their life, such as work or children, with their newfound day-to-day responsibilities as a caregiver. Many of them put pressure on themselves or felt pressure from other family members to fulfil their role as a caregiver successfully. Caregivers also experienced language barriers that prevented them from understanding medical information and communicating their needs. Most of these individuals were also unfamiliar with the term palliative, and engaged in self-learning to overcome this barrier.

To cope with these challenges, caregivers relied on religion and spirituality. They also tried to block out negative aspects of the experience and focus on the positive. Taking part in hobbies or activities also served as an effective but temporary distraction that allowed them to remove themselves from the experience for a short period of time. These coping mechanisms gave caregivers the strength to move forward through the experience, manage their caregiving duties, and cope with their grief.

Throughout the experience caregivers appeared to receive and expect the most support from their family members. Some people received support from friends and co-workers, which was also found valuable. There were also various HCPs involved in the care that offered different forms of support. However, physicians, nurses and PSWs were mentioned the most in the re-telling of their experiences. Some caregivers felt well supported and were surprised to learn the value of PSWs. In contrast, other caregivers felt that the physicians or nurses had not shared enough information with them, weakening their trust in the health care team. Ultimately, all caregivers felt that the experience had changed the way in which they viewed life and death. Many participants revaluated their values and their priorities in life, while others contemplated their own death more willingly.

CHAPTER 5

DISCUSSION

This study provides further insight and knowledge into aspects of South Asian caregivers' experiences of caring for family members who are dying. It also sheds light on new aspects of the experience that have not been well detailed in previous literature. In particular, there were four key findings in this study: (a) cultural attitudes had an impact on caregivers' decisions; (b) obstacles faced by South Asian caregivers; (c) foods varied and important role in the experience and; (d) the impact of HCP-caregiver relationships on the experience.

Cultural Attitudes Had an Impact on Caregiving, Death and Dying

One of the most significant findings of this study is the influence and impact of culture on South Asian caregivers' experiences and their perceptions, in the context of EOL care. The findings reveal that culture plays a role in caregiver experiences but to varying degrees. As caregivers shared their journey, it was evident that they experienced some form of cross-cultural conflict at points in their experience, during which time they began to recognize differences in customs, values and norms (Choi, 2014). This experience of cross-cultural conflict and the journey to overcome this conflict is well explained by the Theory of Cultural Marginality (Choi, 2014). The theory postulates that immigrants experience cross-cultural conflict and have varying responses to this conflict that range from assimilation to rejection of the new culture (Choi, 2014). Few caregivers described themselves as fully assimilated into Canadian culture and integrated into society (Choi, 2014), indicating that the integration of their South Asian cultural customs or traditions into the care of their dying family member and in the EOL were not a priority. Other individuals felt that assimilation would mean denying their own culture. Thus they described a strong connection to their culture and wanted to maintain traditions and customs especially when receiving a palliative approach to care and in the EOL stages (Choi, 2014). Most caregivers appeared to merge both cultures and lifestyles (Choi, 2014), melding South Asian customs and traditions with the Canadian lifestyle. For example, when contemplating their own death, some caregivers explained that their expectations for their future personal and health care changed based on the lifestyle in Canada. These caregivers wanted to avoid burdening their children, and expected to be placed in LTC homes, a notion that was previously considered neglectful in their community. Caregivers also felt that it was important to have discussions about their own death with their family members in relation to their future care. Thus, caregivers maintained the importance of filial duty but understood that its expression may change in accordance with their lifestyle. This new insight demonstrates personal growth (Williams, 2014) and illustrates efforts in easing cultural tension (Choi, 2014).

Regardless of caregivers' level of connection to their culture, it was evident that their cultural background pervaded their own experience in some manner. While the expressions of culture varied from person to person, its influence on an individual's personality, values, relationships and perspectives is undeniable (Wan & Chew, 2013). Thus, culture could also influence their interpretation or recall of events. As such, even when caregivers described a limited sense of connection to South Asian culture, its presence was still evident in their behaviours, interactions and environment. For example, one caregiver felt that culture was unimportant in the context of EOL, but wanted to maintain her culture in her daily life. This was also evident during the interaction, as she was dressed in cultural attire, offered cultural foods and did express some cultural values in the re-telling of her experience. Thus, there are contextual and personal factors that influence the degree of cultural expression and acculturation (Choi, 2014). Furthermore, individuals that are aware of the impact of culture on aspects of their personality and life often have a stronger sense of cultural identity (Lu & Wan, 2018). Alternatively, development of multicultural identities will occur in cases where individuals who are exposed to more than one culture simultaneously (Wan & Chew, 2013), as with many caregivers in this study.

Despite the varying degrees of cultural influence in caregivers' experiences, there were some key South Asian cultural ideas related to EOL care that emerged: (a) filial piety; (b) reluctance to move family members into LTC homes or hospice care and; (c) refraining from sharing medical information with family members.

Filial Piety

All caregivers in the study expressed feeling a sense of duty or obligation to take care of their elderly family members in the EOL. While they acknowledged that it was difficult to be a caregiver, they did not regret their decision or express resentment towards their family members. There was a unanimous sense of acceptance and agreement among the caregivers that it was an unspoken expectation to care for family members as they aged, while they were ill or nearing death. These findings are supported by previous literature, which suggests that younger South Asian family members were expected to care for their elderly family members (Radhakrishnan et al., 2017; Venkatasalu et al., 2013; Weerasinghe & Maddalena, 2016). This sense of duty and obligation towards their family members is synonymous with the Confucian value of filial piety, often upheld in East Asian cultures. The principle of filial piety focuses on demonstrating honour and respect towards elderly family members (Sun, Ong & Burnette, 2012).

Caregivers' lack of resentment towards family members and acceptance of their role can be attributed to their expression of filial piety. Studies have found that Chinese caregivers who valued filial piety were more likely to have a positive perception of caregiving (Lai, 2010; Sun et al., 2012). This included perceiving caregiving to be a more positive experience, less financially costly and personally beneficial (Lai, 2010). In contrast, it can also cause stress, as reported by Chinese-American caregivers, who felt acculturation and differences in beliefs among family members may result in different expressions of filial piety, feelings of obligation and disagreement among family members regarding care decisions (Sun et al., 2012). Caregivers in this study felt similarly, as they acknowledged their Canadian lifestyle was not conducive to fulfilling their role as caregivers, as envisioned within the context of South Asian culture. In particular, they found it challenging to uphold their filial duty while maintaining their other roles and responsibilities, such as going to work, caring for children and completing house work. This was compounded by the lack of community or social network and the difficulty in accessing resources.

Reluctance to Move Family Members into LTC homes or Hospice Care

Filial piety also affected caregivers' decisions regarding hospice care and LTC homes. South Asians were found to be less likely to consider moving elderly family members into nursing homes, due to the sense of filial piety (Gupta, 2002). Interestingly, some caregivers acknowledged that perhaps the LTC home or hospice care was potentially a good option or a necessary option given the challenges of caring for a dying family member at home. However, caregivers unanimously were unsatisfied with moving their family members into a LTC home or hospice for various reasons. There was an overall sense of guilt associated with this decision, as caregivers in the study reported that moving their family members into a LTC home would be morally wrong. For these caregivers, they were particularly concerned about their family member's perceptions or feelings of loneliness and neglect in their illness and in death. Essentially, moving their family members to a LTC home or hospice was equated with abandonment of their family member. They also felt that moving their family member into a facility would elicit negative emotions and be psychologically distressing for the family member as they would be acutely aware of their mortality and impending death. Chinese-American caregivers of family members with dementia reported having similar ideas, and felt that by institutionalizing family members they were abandoning their responsibilities as caregivers (Sun et al., 2012; Hicks & Lam, 1999).

South Asian caregivers in the study demonstrated a poor understanding of hospice care. They perceived hospice care to be an unwelcoming and uncomfortable environment for their dying family member. While some caregivers expressed a general understanding of its purpose, they were reluctant to accept it as a suitable place of death, citing it to be a lonely place and a negative symbol of death. The Latino community in particular had similar perceptions of hospice (Cagle et al., 2016; Cohen, 2008; Kreling et al., 2010). This indicates that there is still a significant need for education about this care setting. Overall, ethnic minorities have been reported to have lower levels of knowledge of hospice and inaccurate perceptions, which leads to lower rates of utilization (Cohen, 2008). However, language barriers and cultural values prevent ethnic minorities from using hospice care. It is also important to consider whether these facilities acknowledge cultural needs in their approach to care.

This finding strongly supports previous literature that suggestions South Asian immigrants demonstrate a lack of awareness of the available palliative care and EOL care resources available to them, thereby decreasing their quality of care (Biondo et al., 2017; Doorenbos, 2003; Evans et al., 2012; Khosla et al., 2016; Owens & Randhawa, 2004; Radhakrishnan et al., 2017; Randhawa et al., 2003; Wilkinson et al., 2016; Worth et al., 2009). Therefore, efforts needs to be made to educate this population regarding the potential benefits of hospice or LTC homes and introduce initiatives to normalize the subject of death and the use of these facilities.

Refraining from sharing medical information with family members

There was a significant focus on remaining positive throughout the experience and maintaining a hopeful outlook. Consistent with similar findings in previous literature (Khosla et al., 2017; Sharma et al., 2012), this often involved withholding information from the dying family members regarding their physical condition. There was a shared notion that telling dying family members about their condition would have a negative impact on the psychological and physical well-being, thereby hastening death. Caregivers viewed themselves as protectors of their family members' well-being and were self-sacrificing by taking on the burden of knowledge, decision-making and prioritizing their family member. According to a literature synthesis, the desire to withhold information from ill family members is also expressed in Italian, Filipino, Arab, Mexican, and Chinese cultures (Bosma, Apalan & Kazanjian, 2010; Kreling et al., 2010). These groups had similar rationale for this decision, as they believed telling family members that they were going to die would decrease hope and would bring about bad luck (Bosma et al., 2010).

Unfortunately, the practice of family members withholding information from the patient contradicts HCPs' ethical and professional duty to the client, to share information, maintain confidentiality, and facilitate patient autonomy (College of Nurses of Ontario, 2009). Although caregivers in this study did not describe any challenges or conflicts with HCPs regarding the right to share or withhold information from their dying family members, there were other factors that contributed to these circumstances. Often, dying members who could not speak English were not offered translators. In these instances, caregivers took on the role of the translator and decision maker. In these instances, patients were not afforded the opportunity for autonomy and privacy.

Overall, there are important cultural considerations to make when interacting with South Asian caregivers. While there are shared cultural beliefs and attitudes, individual expressions of culture will be unique. Therefore, HCPs need to be aware of these personal and contextual factors while practicing person-centred care.

Obstacles Faced by South Asian Caregivers

The overall caregiving experience appears to transcend demographic or contextual differences. Caregivers of varying ethnic backgrounds have described a variety of challenges they encountered during their experience that are similar to those expressed by South Asian caregivers in this study (Hudson et al., 2010; Ventura et al., 2014). For instance, there are several unmet needs among these caregivers including psychosocial, physical, practical, informational and communication needs (Hudson et al., 2010; Ventura et al., 2014). This includes poor communication with HCPs, isolation or loneliness, a lack of sufficient information, and a lack of support with daily physical tasks (Ventura et al., 2014). Despite these challenges, caregivers demonstrated commitment to their role by maintaining their responsibilities, making their family members a priority, providing comfort, and engaging in acts that bring emotional fulfilment and satisfaction to the caregiver (Williams, 2014). Thus, there are universal themes, ideas and challenges that are shared among caregivers of varying backgrounds and experiences. Despite these commonalities, the specific context of the experience and other caregiver factors will create unique challenges and generate some different experiences, as evidenced by a comparison of the findings of Parveen and colleagues (2011).

Parveen, Morrison and Robinson (2011) compared Indian, Pakistani, Bangladeshi and Caucasian caregivers' experiences in the UK. Similar to the South Asian caregivers in this study, South Asian participants in the study by Parveen and colleagues felt more extrinsic motivation to be caregivers, such as a sense of duty and obligation that stemmed from socio-cultural expectations (Parveen, Morrison & Robinson, 2011). In particular, these caregivers felt that there was no one else who would take on the role of a caregiver, and the duty fell to them. In comparison, Caucasian participants described feeling more intrinsic motivation to care for their family members, namely their caring nature, their perceptions of their relationships or emotional bonds. While both ethnic groups felt a sense of duty to take on the caregiver role, they had different motivations and rationales for doing so. Therefore, this study highlights the importance of taking culture into consideration and taking a person-centred approach, as each caregiver experience will be different in some manner.

Furthermore, South Asian caregivers in this study felt supported by family members, they also described receiving criticism from family members regarding care decisions and feeling immense pressure to satisfy all parties involved in the experience. There was dissatisfaction and conflict that arose among other family members regarding care decisions for their dying family member. Disagreements occurred over placement in a LTC home, sharing of information or post-death rituals. Caregivers expressed wanting to seek out external formal supports, such as placement in a LTC home or hiring a PSW, but were met with disapproval by other family members. Despite this conflict, caregivers continued to largely rely on their own family members for support, especially in bereavement, which is in contrast to the findings by Parveen and colleagues. This level of pressure and burden can cause caregivers to feel unappreciated and lonely (Stenberg, Ruland & Miaskowski, 2010).

While there is an increase in interventions to improve the well-being of caregivers and provide support, the applicability of these interventions to different cultures has not been tested (Hudson et al., 2010). For example, Cruz-Oliver et al. (2016) created a culturally sensitive education intervention intended to improve the quality of life of Latino family caregivers. The education intervention provided information about caregiver stress, coping and the benefits of professional support. They found that education helped to increase caregiver self-awareness, and improve their knowledge about the availability of resources and the benefits of accessing resources (Cruz-Oliver et al., 2016). The findings of the study also suggest that these types of educational initiatives have the potential to be adapted to other ethnic minorities and cultures (Cruz-Oliver et al., 2016).

South Asian caregivers in this study also indicate potential interest in developing such supports and educational initiatives, as they attributed their decision to participate in the study to their desire to help future South Asian caregivers from experiencing similar challenges. Therefore, it is evident that these South Asian caregivers recognize the gaps in care and the steep learning curve associated with transitioning into this role.

Food's Varied and Important Role in the Experience

Another key finding of this study was the significant and varied role of food throughout the experience. Food sometimes took on a formal role, as part of a death ritual. However, it most often played an informal role in the experience. For many caregivers, food marked important points in the experience.

Food was often portrayed as a symbol of life and a measure of health and well-being. The ability to consume food can be viewed as a marker of well-being, while the inability to eat indicated that EOL was near (Rio et al., 2012). Food can also play an important role in ensuring a good death (Connolly, Sampson & Purandare, 2012; Gatrad, Choudhury, Brown & Sheikh, 2003). The withdrawing of food was sometimes viewed as the hastening of death and not conducive to a "good death". This idea was influenced by religious beliefs, as evidenced in the Sikh, Hindu and Muslim religions (Gatrad & Sheikh, 2002; Gatrad et al., 2003; Jhutti-Johal, 2013). The withdrawing of food was considered unnatural and interfering with the natural process of death (Bülow et al., 2008; Jhutti-Johal, 2013). As another example, in Taiwanese culture, it is believed that not feeding an individual at the EOL might mean the person would die hungry, resulting in a restless and hungry soul (Rio et al., 2012). Therefore, in order to ensure a "good death" ethnic minority groups are more likely to receive artificial nutrition at the EOL, most likely motivated by their religious faiths (Connolly et al., 2012; Gatrad et al., 2003). For caregivers the importance of food and understanding of artificial nutrition and hydration in the EOL is not congruent with that of scientific and health-based evidence. Therefore, this may cause conflict or misunderstanding between the HCPs and clients. Although the misunderstanding surrounding artificial nutrition and hydration is not unique to South Asian culture, certain aspects of the relationship with food are unique, such as the types of traditional foods, the religious symbolism of food, and the use of the food in cultural practices (Clegg, 2003; Gatrad & Sheikh, 2002).

Food was also a source of comfort and a symbol of support for both caregivers and family members. Similar to East Asian cultures, providing food to their family members was deemed an expression of affection (Chai, Krishna & Wong, 2014; Payne, Seymour, Chapman & Holloway, 2008). This further lends itself of the notion that South Asian caregivers exercise filial piety. It was important to caregivers to make their dying family member's favourite foods, as this was a gesture of care and considered part of their duty as caregivers. In many cases the dying family member would only be able to eat one bite or merely smell the food for a sense of satisfaction and instant gratification. Despite this, caregivers felt satisfied with having been able to fulfil small wishes and in being able to demonstrate their affection. However, one caregiver described the stress she felt in being forced to make, deliver and feed traditional foods to her family member in the hospital and the LTC home, due to the unavailability of culturally familiar foods in these facilities. Literature suggests that there are often tensions between the provision of Western food and ethnic food in facilities, such as hospitals (Evans et al., 2012). This proved to be a significant source of stress for Indian immigrants living in Australia, who felt burdened with this extra task when caring for family members in inpatient settings (Shanmugasundaram & O'Connor, 2009).

In another example of food as a source of comfort, relatives brought food for caregivers following the death of their family member, in a gesture of support. Providing food for the family during bereavement would allow the family to focus their time and energy on grieving, rather than other daily activities (Parkes, Laungani & Young, 2015).

Chai et al. (2014) describe the perspectives of Singaporean Chinese patients and caregivers related to food, which are similar to the perspectives expressed by South Asian caregivers. In particular, both groups describe food as a symbol of hope, as a right, and in having the ability to strengthen bonds (Chai, et al., 2014). Food is also a part of cultural identity and maintaining certain foods can help create and preserve a sense of connection and belonging to cultural group as well as personal identity (Lam & Keller, 2015).

Caregivers' relationships with food suggest that food plays an important and varied role in the caregiving experience. In examining these relationships, HCPs can gain an understanding of how to address and incorporate discussions about food habits, preferences and diet into their care, within a cultural context. However, literature also suggests that making assumptions about food preferences based on ethnicity can lead to stereotyping or fail to address a person-centred approach to care (Evans et al., 2012). This illustrates the challenges in demonstrating cultural sensitivity. While HCPs must be aware of cultural ideologies, it is important to maintain a person-centred approach, without making assumptions about patient needs.

The Impact of Health Care Provider-Client Relationships on the Experience

The fourth key finding was the perceptions of HCP roles and relationships within the South Asian community. Although not explicitly stated, caregivers' perceptions of HCPs revealed a hierarchy of power among HCPs. Furthermore, caregivers' perceptions of their family members' well-being and the quality of care affected their relationships with HCPs. Upon reflecting on their experience, caregivers re-evaluated their perceptions of the HCPs, disrupting the perceived hierarchy of power.

Some caregivers expressed the notion that doctors were equivalent to God. This finding has been recorded in a few studies on immigrants and the Aboriginal population in other health care contexts, but has not been explored well in the literature (Bubela, 2015; Shahid, Finn, Bessarab & Thompson, 2009; Bottorff et al., 1998). There was a high level of trust placed in the doctors, a finding also reported by Gopichandran and Chetlapalli (2013) conducted a quantitative study in Southern India to determine the factors that influence patients' trust in doctors. They found that South Indians' level of trust was largely affected by the doctor's behavioural competence, the patient's level of comfort in approaching the doctor, and their perception of the doctor as a relatable individual (Gopichandran & Chetlapalli, 2013). Similarly, some South Asian caregivers in this study, who were able to communicate with the doctor clearly, expressed feelings of high trust, support and satisfaction with care. For many, it was the trust that doctors had sufficient empirical knowledge to make care decisions effectively and had the insight to understand caregivers' and their families' needs. While cultural competence had a minor influence in their level of trust, the ability to speak the same language did improve perceptions of care quality (Gopichandran & Chetlapalli, 2013).

However, Gopichandran and Chetlapalli (2013) explored South Asians' perceptions of doctors in India and there are contextual influences that may result in different perceptions in India. In particular, although the views of South Asian caregivers in this study initially identified with the findings of Gopichandran and Chetlapalli, this perceived power hierarchy among HCPs was disrupted following the experience of caregiving. In particular, caregivers who once viewed physicians at the top of the power hierarchy began to question their decision making skills. As such, it is important to acknowledge that South Asian caregivers may arrive with certain expectations and preconceptions of HCPs. HCPs need to acknowledge these expectations and clarify roles in order to ensure that caregivers can continue to trust HCPs and have realistic expectations for care.

There were also some misconceptions or stigmas associated with paid caregiving roles, namely PSW or nurse roles. Some caregivers were reluctant to allow strangers into their homes, a finding that was also acknowledged in a study by Bowes and Wilkinson (2003). Bowes and Wilkinson (2003) found that South Asians wanted in-home services, but had difficulties in allowing strangers and people with unclear roles into their homes. Caregivers' lack of understanding of PSW and nurse roles appeared to be rooted in socio-cultural ideas that influenced their perceptions of these professions in Canada. In particular, caregivers were either unaware of PSWs, were unclear of their role and purpose or acknowledged the presence of stigma associated with this role within their respective communities. In particular, Sri Lankan caregivers reported that the professions of the PSW were not viewed as a respectable position, due to the nature of the job. These misconceptions and stigmas are likely rooted in the hierarchy of power in health care led by doctors (Aluwihare-Samaranayake & Paul, 2013). In Sri Lanka, perceptions of the profession of nursing were influenced by the dominance of the medical profession and the existence of patriarchy within the health care setting (Aluwihare-Samaranayake & Paul, 2013). The socio-cultural idea that women are subordinate to men translated into the health care setting (Aluwihare-Samaranayake & Paul, 2013), and this was evident in one caregiver's own perception of nurses in Nepal, stating that it was considered taboo for women to work with men. Cultural notions further perpetuated the perception of nurses as powerless due to the nature of their professions (Aluwihare-Samaranayake & Paul, 2013; De Silva & Rolls, 2010). Nurses are burdened with an intense workload which makes them task-oriented leading to a lack of decision-making ability and lack of opportunity for skill development that is further hindered by the unofficial power hierarchy (De Silva & Rolls, 2010). This power hierarchy is not unique to South Asian culture, and can be found within Western society (Price, Doucet & Hall, 2013). However, the existence of a power hierarchy compounded by cultural taboos and language barriers brings forth South Asian immigrant misconceptions more prominently, contributing to difficulty in accessing appropriate support resources.

Although caregivers did not necessarily uphold these views themselves, the presence of these ideas within their community hindered their ability to seek out PSW support. For example, one caregiver recognized the need for extra support. As a solution, she sought to hire a PSW that was of the same cultural background and spoke the same language. However, cultural taboos and stigmas hindered the PSW from accepting the job offer. Other caregivers did not recognize the value in hiring a PSW and felt their presence would not drastically change their circumstances. It was only after they had the opportunity to involve the PSW that they began to truly value the role and acknowledge the importance of the PSW.

Despite the caregivers' perceptions and misconceptions, they acknowledged that culture is ever changing and that these stigmas or misconceptions may not be as prevalent among future generations. This was attributed to the contrast of Canadian culture and the progressiveness of society. However, it is important that HCPs acknowledge these possible misconceptions and consider exploring the individual's current perspective and views on their expectations for care, their understanding of the role each member of health care team, and whether there are cultural implications for care.

Summary of Discussion

Based on the findings of this study, it is evident that there are important factors to consider and understand when caring for the South Asian population in the end-of-life. There are many similarities among the caregivers in this study that can help HCPs understand the South Asian culture within the context of the palliative approach. However, it would be counter-productive to assume that this new knowledge of the South Asian experience will be replicated in every South Asian patient experience. As emphasized by the Theory of Cultural Marginality, it is important to consider both contextual and personal factors when approaching a population (Choi, 2014). Therefore, HCPs must recognize that although two individuals who share the same cultural background may share similarities in their cultural ideas, the degree to which they uphold these cultural values, beliefs and preferences will vary. The findings of this study will allow HCPs to increase their comfort in approaching South Asians within the context of the palliative approach, but should not limit HCPs from pursuing a person-centred and family-centred approach to care.

CHAPTER 6

STRENGHTS, LIMITATIONS, IMPLICATIONS AND CONCLUSION

Strengths and Limitations

Strengths of study include the recruitment of participants with lived experiences as South Asian caregivers and as South Asian immigrants. The inclusion of participants with lived experiences as caregivers allowed for a more trustworthy and credible description of the phenomenon and the challenges faced by this unique group. Non-English speaking participants were also included, thereby producing findings with increased transferability and contributed to the credibility of the findings. Credibility was further enhanced by the use of investigator triangulation.

There were a few limitations in this study. There was a potential for sampling bias as participants were only recruited through a community hospice and community health centre in one urban region in Ontario. These participants were offered access to EOL care and bereavement support resources. A few participants made use of the formal bereavement support resources. In being offered the opportunity for access and support through formal resources, these participants were more likely to receive more support during their time as caregivers and in their bereavement. Therefore, their experiences might differ from those who did not receive resources or support from these services. This may also reflect a 'best case' and affect transferability of findings.

Furthermore, there were participants who were more than one year bereaved. This may result in a recall bias, as literature suggests that interviews conducted earlier in the bereavement period are likely to result in better recall of experiences (Bentley &

O'Connor, 2015; Hynson et al., 2006). Reports in the literature also suggest that bereaved individuals should be able to decide when they are willing to be interviewed, as the emotional readiness to talk about a difficult experience is subjective (Bentley & O'Connor, 2015). As such, caregivers must be given enough time to be able to grieve their loss and feel emotionally ready to engage in the study. However, this may result in caregivers who are more than one year bereaved, thereby lending the study to recall bias.

While there were participants from varying backgrounds, experiences of individuals from all South Asian countries were not captured. This was largely due to difficulties in accessing this vulnerable population through the recruitment partners and individual willingness to participate. Based on the findings in this study, it is evident that there are some differences between South Asian sub-cultures with regards to customs and values. Once again, this may limit the transferability of findings. This limitation was addressed by recruiting a heterogeneous sample, with regard to country of origin, may have increased the transferability and trustworthiness of the findings (Patton, 2015).

Finally, although efforts were made to include male participants, a majority of participants were female caregivers. Thus, the male perspective may not have been fully represented. There were also no experiences that involved sibling relationships or parents caring for adult children. The dynamics of these relationships may present different and unique challenges, thereby eliciting a different caregiver experience.

Implications for Practice

The study findings provide several important implications for practice for HCPs in varying settings. Culture plays an important role in the delivery of wholistic care

(CHPCA, 2013), as cultural values, beliefs and practices influence the care plan and care decisions. Therefore, it is the responsibility of all HCPs to incorporate these cultural factors into the delivery of care, within their scope of practice. In particular, HCPs need to identify the impact of culture on the client-HCP relationship, acknowledge the importance of incorporating family members in the circle of care, proactively identify potential cultural differences caregiver challenges, proactively provide interventions or solutions to overcome challenges, and make efforts to strengthen HCP-client communication.

Cultural differences in perceptions of quality of life and EOL care practices, can affect the relationship between the HCP and clients and their families. Therefore, HCPs need to identify these cultural differences as well as the clients' personal values, beliefs and perceptions in order to build a therapeutic relationship and pursue a person-centred. In addition to meeting the needs of clients receiving care, HCPs also need to identify and address the needs of family members or friends involved in the circle of care, especially with regards to bereavement support, psychosocial support, physical support, spiritual support, as well as decision making, respite care and education (CHPCA, 2013).

Family caregivers are often heavily involved in the care decisions and these decisions are often made in the context of their own personal experiences and values, with varying degrees of cultural influence. Regardless of the personal importance of cultural values, HCPs need to explore the manner in which clients and families define and identify culture in their own context. Doing so will support the delivery of a person-centred and family-centred palliative approach to care, that is culturally sensitive.

The findings of the study provide a baseline understanding of the challenges faced by South Asian family caregivers, as well as supports they received, the degree of cultural impact on the experience and the impact of other factors on the experience. It highlights that the experiences of South Asian family caregivers and their families are complex, complicated by a variety of factors that HCPs may not be aware of. Using this information, HCPs can be more aware of the potential cultural differences, values and practices, as well as the impact of socio-cultural issues on quality of care and the patient's well-being (Betancourt, Green, Carillo & Owusu Ananeh-Firempong, 2016). For example, it is important that HCPs identify family dynamics when caring for patients, as families of ethnic minority patients are more likely to be involved in decision-making (Casarett, Crowley, Stevenson, Xie & Teno, 2005). HCPs can also help to mitigate negative perceptions of LTC homes and hospices by engaging in more thorough education practices with patients and their families regarding the purpose of these facilities. Patients and families had particularly low awareness of the purpose and benefits of hospice services, and this may serve as a barrier to use of these services (Ford, Nietert, Zapka, Zoller & Silverstri, 2008). However, in addition to educating patients and families about hospice, it also important to discuss whether the hospice placement aligns with the goals of care for the patient and the family caregivers.

Furthermore, HCPs can be also more proactive when explaining the availability of other services and supports, such as PSWs. Given that there may be different perceptions of PSWs or a poor understanding of their role, HCPs have the responsibility to make patients and families aware of the availability of this support, their potential benefits and help them link to these services.

Given that communication was one of the biggest challenges outlined by caregivers in this study, culturally sensitive communication training should be developed for HCPs. EOL care communication training has been shown to improve quality of care in a variety of settings (Barth & Lannen, 2010; Cagle, Unroe, Bunting, Bernard & Miller, 2017; Vandrevala et al., 2017). However, it is important to ensure that the communication training incorporates cultural factors, such as the South Asian perspective of death as a taboo subject (Biondo et al., 2017; Con, 2007; Radhakrishnan et al., 2017; Spruyt, 1999; Venkatasalu, Arthur & Seymour, 2013; Worth et al., 2009). Furthermore, inaccurate translations for key terms such as palliative care or ACP (Biondo et al., 2017; Evans et al., 2012) also need to be taken into consideration.

Overall, in order to combat the challenges caregivers face, literature suggests that caregiver needs should be incorporated into the care plan, along with the patients' needs (Adelman, Tmanova, Delgado, Dion & Lachs, 2014). In addition, they should also engage in education to learn about their role, the skills they may require, managing stress and identifying outcomes of care. This proactive approach will help caregivers be more self-aware and decrease the likelihood of caregiver burden or stress (Adelman et al., 2014).

Implications for Education

This study has potential implications for HCPs, students, caregivers and the public. First, the findings of the study identify helped to identify gaps in care and strategies for improvement that can be used to inform the development of training and education on culturally sensitive care for HCPs and HCPs in training. In particular, the findings can be incorporated into palliative and hospice care training programs and education interventions for HCPs to improve their cultural awareness, sensitivity and communication skills.

Existing education interventions or programs can be adapted or modified to address the cultural aspects of care when caring for South Asian clients. For example, Kataoka-Yahiro, McFarlane, Koijane and Li (2017) describe adapting two different existing training programs to create a new program based on cultural and communication theories that addresses the cultural aspects of care in Hawaii. The authors found that staff had increased knowledge and confidence in providing palliative and hospice care (Kataoka-Yahiro et al., 2017). Therefore, adapting existing programs that address general South Asian cultural perspectives on death and dying, communication styles and other cultural nuances can help to improve the delivery of a palliative approach to care and quality of care.

Another study by Cruz-Oliver, Malmstrom, Roegner and Yeo (2017) used a video soap opera to illustrate a Latino family caregiver’s challenges in caring for a family member and the role that Latino culture plays in the family caregiver-HCP relationship. The video increased HCPs’ awareness of Latino culture related to caregiver stress and EOL decision making in a culturally sensitive manner. The authors suggest this education intervention can be easily modified for other contexts. As such, the findings of this study can be used to create similar culturally sensitive videos that illustrate common South Asian family caregiver challenges that may stem from cultural differences.

In addition to professional development or continuing education opportunities for existing HCPs, the findings of this study also have implications for undergraduate HCP education and training. Using simulations to help students develop competency and confidence in delivering a palliative approach has been shown to be an effective tool (Kirkpatrick, Cantrell & Smeltzer, 2017). Some existing programs do address cultural aspects of care (Kirkpatrick et al., 2017). Bobianski, Aselton and Cho (2014) developed a simulation on EOL care in a Chinese-American home for undergraduate nursing students. This allowed students to appreciate the importance of integrating cultural values and the impact of cultural views on the experience (Bobianski et al., 2014). Immersing students in a simulated experience that highlights South Asian cultural factors that influence EOL care can support the creation of a culturally safe health care environment.

In addition to creating education initiatives for HCPs, the findings can be used to address the knowledge gaps among South Asian caregivers and the general South Asian population. Caregivers expressed a lack of awareness of palliative and EOL services. Thus, there is a need to educate the South Asian population on the availability of services and supports, as well as encourage self-awareness to promote self-care. Self-care must be maintained in order for the caregiver to maintain their commitment to their role and responsibilities (Williams, 2014). Previous literature has suggested that designing culturally sensitive education sessions to inform caregivers of their role, caregiver burden and self-care strategies are effective (Cruz-Oliver et al., 2016). Therefore, efforts should be made to adapt existing education interventions or create new interventions that address the aforementioned cultural differences and provide education about culturally sensitive care.

Implications for Policy

This study has implications for policies in the palliative sector that will help sustain the delivery of culturally sensitive care to the South Asian population in Canada. These policies should be implemented on a systemic and organizational level in order to facilitate a culturally safe environment in all care settings for South Asians.

There is an overall need to incorporate culture into the delivery of care, especially within the delivery of palliative approach to care. Although culture is identified as an important part of care (CHPCA, 2013), there are very few policies and strategies that have been implemented to facilitate a strong culturally sensitive approach to care. Creating individual policies focused primarily on cultivating a culturally safe environment and delivering culturally sensitive care can support the delivery of the palliative approach to care. For example, caregivers were concerned about communication and felt uninformed regarding the process of transitioning their family members into EOL care. Therefore, policies are required in order to ensure that caregivers are well-informed about the palliative approach and the goals of EOL care. This can be achieved by ensuring caregivers are included in the plan of care and are offered the benefits of a palliative approach to care (CHPCA, 2013).

In order to further ensure caregivers are supported and well-prepared for their role, engaging caregivers and patients in ACP is essential (CHPCA, 2013). In facilitating open and clear communication, and providing caregivers with time to comprehend new information, ask questions and discuss options, a patient and family-centred palliative approach to care can be achieved. Other systemic changes that can be made in the approach to care include developing community programs, offering culturally sensitive support groups, allotting time for education and offering resources that are accessible to the South Asian population (CHPCA, 2013).

Organizational policies are vital in promoting culturally sensitive care. Given the South Asian caregivers' negative perceptions and misconception of LTCs and hospices, these facilities especially should work to develop policies that can mitigate these negative perceptions and create a culturally safe environment. Especially given that there is low hospice utilization among ethnic minorities, it is important that there are policies created and enforced that facilitate the incorporation and recognition of culture to encourage hospice use among the South Asian population. In particular, policies should be placed to encourage administrators and HCPs working in these facilities to recognize the importance of psychosocial and spiritual aspects of care, in addition to physical needs (Bosma et al., 2010). Policies that mandate continued education and professional development with regards to culturally sensitive EOL care clinical knowledge and communication can also improve the quality of care (Bosma et al., 2010).

Implications for Research

There are several implications for future research arising from this study. Although this study focused on the larger South Asian population, the findings indicate that there are some differences between the sub-cultures of South Asian groups. In this study, negative and stigmatizing perceptions of PSWs were more common among individuals coming from Sri Lanka and Nepal. Thus, future research should focus on exploring and comparing existing stigmas against PSWs between South Asian sub-cultures, as well as attitudes towards other HCPs.

It is also important to acknowledge the cultural differences, compounded by religious differences, across the large and diverse country of India. In providing individuals of different origins with a voice, HCPs can continue to increase their knowledge and awareness of different cultural perspectives they may encounter in their work. Therefore, future research should focus on including each sub-culture to highlight important similarities and differences that may impact clients' and caregivers' experiences. Doing so will help HCPs gain a deeper understanding of South Asian culture and inform the development of targeted programs and interventions that cater to important sub-cultural differences.

Future research is needed on caregiver burden and stress within the South Asian community, as well as the effectiveness of interventions developed for this population. While previous literature has shown that education and support interventions for caregivers are effective in reducing stress and burden among caregivers (Adelman et al., 2014; Hudson et al., 2010), these interventions have not been adapted or tested among ethnic minorities (Hudson et al., 2010). Most of the previous literature exploring the experience of South Asian patients and families has used qualitative methods. As such, there is a need for more quantitative studies to support the qualitative findings. Using a mixed methods approach would help to gain a deeper understanding of the experience and to evaluate the effectiveness of interventions and outcomes, such as caregiver burden, hospice utilization and accessing of resources or supports.

While previous research compared the perspectives on death and dying of first and second generation South Asians (Sharma et al., 2012), however this study was weak in its methodology and participants in this study were not caregivers. Conducting research that addresses the experiences of first and second generation South Asian caregivers can provide further insight into the importance of culture within a palliative approach. The degree of acculturation and individual responses to cultural marginality are affected by several factors (Choi, 2014), which in turn will impact the experience of caregiving.

Finally, most studies on the experiences of South Asian caregivers have applied qualitative methodology. Therefore, future research should apply quantitative methodology or mixed methods methodology to measure caregiver burden and stress among this population, rates of access or use of palliative services and measure the perceived quality of care and effectiveness of interventions.

Conclusion

South Asian caregivers face several challenges and barriers when caring for their dying family members. Although caregivers of varying backgrounds share similar experiences and challenges, this study highlights the impact of cultural differences on the caregiving experience. It is evident caregivers face several challenges that prevent them from accessing and utilizing available resources. Furthermore, caregivers are also challenged with upholding cultural values and customs within a western society. These challenges are exacerbated by the lack of culturally sensitive health care resources available to them. As such, caregivers' quality of life suffers. To combat these challenges, HCPs need to address caregiver needs and facilitate a relationship in which caregivers can engage in open and clear communication. Furthermore, this study highlights the need for culturally sensitive education for HCPs and the implementation of resources tailored for the South Asian population. Developing these initiatives will facilitate the delivery of culturally sensitive person-centred and family-centred care, as well as improve the quality of life for South Asian caregivers.

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Appendix A

Glossary

Acculturation: Adopting practices and values of another culturally dissimilar group as a result as a result of contact with culturally dissimilar people, groups, and social influences (Gibson, 2001)

Advance care planning: The process of identifying and conveying your wishes for your personal and health care in the end of life or in the event that you are unable to communicate (Speak Up, 2017)

Culture: A set of values, beliefs and information that shape attitudes and have significant meaning among a social group (Registered Nurses' Association of Ontario, 2007)

Cultural competency: Behaviours, attitudes and policies in a system and across professionals that enable the delivery of care cross-culturally (Registered Nurses' Association of Ontario, 2007)

Cultural humility: Cultural humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined population (Tervalon& Murray-Garcia, 1998)

Cultural safety: Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system and creates a safe environment for people to receive health care that is free of racism and discrimination (First Nations Health Authority, n.d.)

Diaspora: The dispersion of people from a single geographical area or homeland (Oxford University Press, 2017)

End-of-life care: Care provided for individuals who are terminally illness, chronic illness or serious illness and have a foreseeable death in the near future (Fowler & Hammer, 2013)

Family member: In this study, family member refers to any relationship that the participant defines as family. This is not limited to ancestral relatives, but extends to spouses, friends etc.

First generation immigrant: Individuals that are born outside of Canada currently residing in Canada as temporary permanent immigrants. This also includes individuals that immigrated to Canada as refugees or have a work or study permit (Statistics Canada, 2016)

Interpretive description: A qualitative methodology developed that uses an inductive analytic approach within clinical research to describe, understand and assign meaning to clinical phenomena (Hunt, 2009; Thorne, 2016; Thorne, Kirkham, O'Flynn-Magee, 2004).

Palliative approach: Maintaining quality of life by providing palliative care services to the patient and family as they move forward through the illness trajectory (Bacon, 2012).

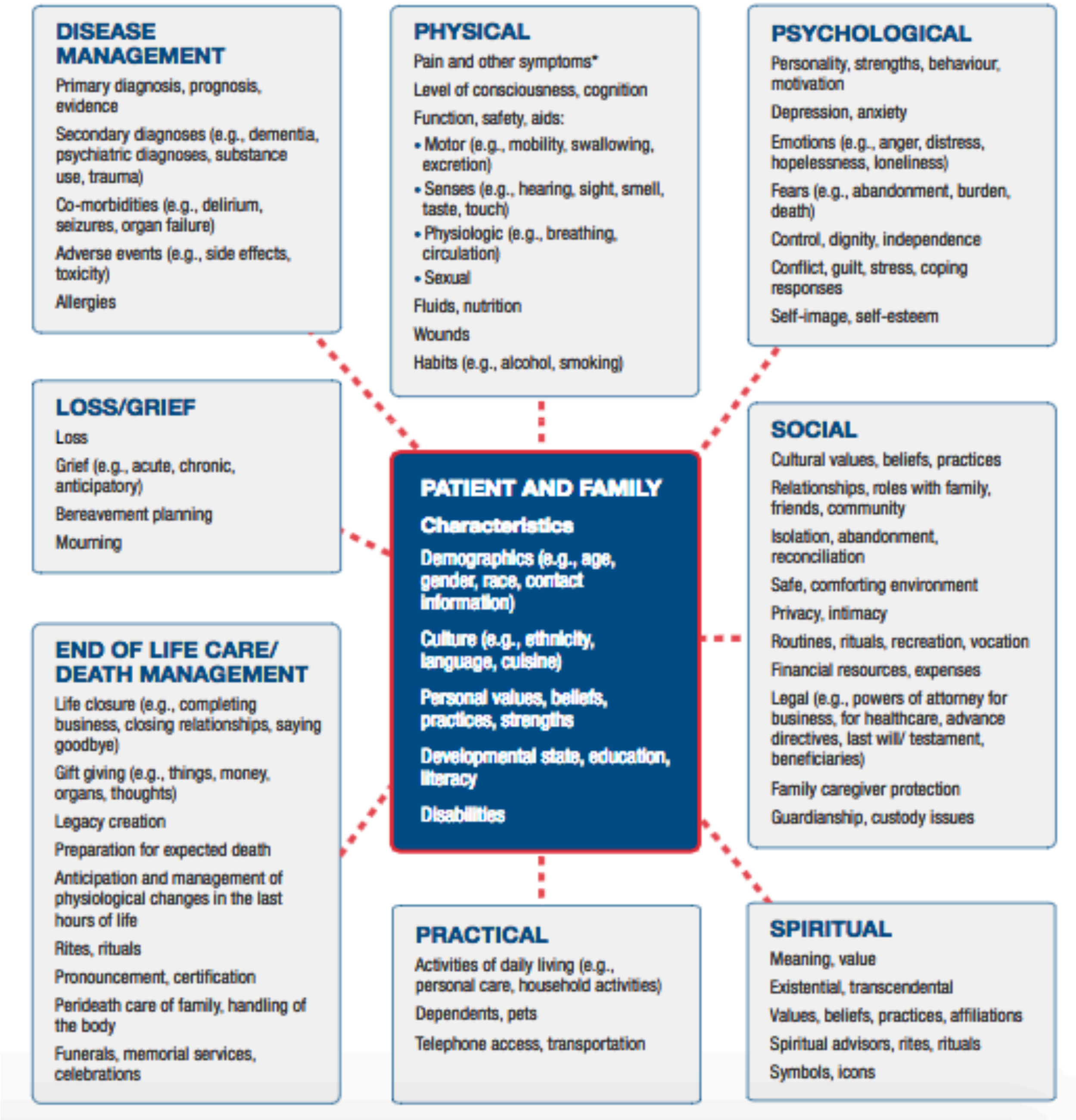
Palliative care: Wholistic approach to care that intends to improve the quality of life of patients and their families, when they are diagnosed with a life-limiting or life-threatening illness (World Health Organization, 2017)

Second-generation: Individuals that were born in Canada with at least one parent who was born outside of Canada (Statistics Canada, 2016)

South Asian: Descendant from Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan or Sri Lanka (Statistics Canada, 2017b)

Appendix B

CHPCA Model for Domains of Issues Associated with Illness and Bereavement



DISEASE MANAGEMENT

Primary diagnosis, prognosis, evidence

Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)

Co-morbidities (e.g., delirium, seizures, organ failure)

Adverse events (e.g., side effects, toxicity)

Allergies

PHYSICAL

Pain and other symptoms*

Level of consciousness, cognition

Function, safety, aids:

- Motor (e.g., mobility, swallowing, excretion)
- Senses (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual

Fluids, nutrition

Wounds

Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL

Personality, strengths, behaviour, motivation

Depression, anxiety

Emotions (e.g., anger, distress, hopelessness, loneliness)

Fears (e.g., abandonment, burden, death)

Control, dignity, independence

Conflict, guilt, stress, coping responses

Self-image, self-esteem

LOSS/GRIEF

Loss

Grief (e.g., acute, chronic, anticipatory)

Bereavement planning

Mourning

PATIENT AND FAMILY

Characteristics

Demographics (e.g., age, gender, race, contact information)

Culture (e.g., ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL

Cultural values, beliefs, practices

Relationships, roles with family, friends, community

Isolation, abandonment, reconciliation

Safe, comforting environment

Privacy, intimacy

Routines, rituals, recreation, vocation

Financial resources, expenses

Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)

Family caregiver protection

Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT

Life closure (e.g., completing business, closing relationships, saying goodbye)

Gift giving (e.g., things, money, organs, thoughts)

Legacy creation

Preparation for expected death

Anticipation and management of physiological changes in the last hours of life

Rites, rituals

Pronouncement, certification

Perideath care of family, handling of the body

Funerals, memorial services, celebrations

PRACTICAL

Activities of daily living (e.g., personal care, household activities)

Dependents, pets

Telephone access, transportation

SPIRITUAL

Meaning, value

Existential, transcendental

Values, beliefs, practices, affiliations

Spiritual advisors, rites, rituals

Symbols, icons

(CHPCA, 2013)

Appendix C

Search Terms

1) South Asian or Afghanistan or Afghan or Bhutan or Bhutanese or India or Indian or Nepal or Nepali or Pakistan or Pakistani or Sri Lanka or Sri Lankan *AND/OR*

2) Palliative care or end-of-life care or terminal illness or life-limiting illness or life-threatening illness or death and dying *AND/OR*

3) Caregiver burden or caregiver stress or caregiver support or informal caregiver or family caregiver

Appendix D

List of Included Studies in Literature Review

Author	**Methods**	**Results/Findings**	**Strengths**	**Limitations**
Evans, N., Meñaca, A., Andrew, E. V., Koffman, J., Harding, R., Higginson, I. J., Pool, R., &Gysels, M. 2012	• Systematic review • 13 electronic databases searched • 2 reviewers evaluated methodological quality independently and then compared • Quality assessed using Hawker et al.'s (2006) grading scheme • 45 studies included that focused on ethnic minorities • All studies from England • Most studies published between 2000-2010 (with the exception of a few) • Combined qualitative, quantitative and mixed methods studies using interpretive synthesis	• 24 qualitative studies • 11 mixed method studies • 10 quantitative studies • Most frequent theme among the studies "awareness of services and communication • Overall 7 themes identified: 7 themes: age structure, inequality by disease group, referrals, caregivers, place of care and death, awareness of services and communication, cultural competency	• Search strategy clearly described • PRISMA diagram used • Used two reviewers	• Only included studies form the UK • 10 studies were not graded using the grading scheme due to the method of publication
Gielen, J., Bhatnagar, S., & Chaturvedi, S. K. 2016	• Systematic review • 5 databases searched • 39 studies included • Studies focused on palliative experience, with regards to spiritually, of Indian patients of	• 12 qualitative studies • 21 quantitative studies • 6 mixed methods • Spirituality affects quality of life perceptions	• Search strategy and search terms well-described	• Only English studies included • Excluded conference abstracts and dissertations • Do not describe tool used to grade quality of the studies • Some studies were difficult to assess

	Indian patients living abroad	• Spirituality also affected relationships with family, friends and God • Values related to religion and spiritually affected care decisions • There is an existential dimension to spirituality that focuses on finding meaning in the experience and acceptance of their illness, condition or death		quality because description of methodology was poor • No description of the number of reviewers used
Biondo, P. D., Kalia, R., Khan, R., Asghar, N., Banerjee, C., Boulton, D., & Simon, J. E. 2017 Canada	• Peer to peer inquiry • Participants: 57 South Asian community members • Conducted by South Asian community members who graduated from Patient and Community Engagement Research Programme (PaCER) • 3 step method: Set, Collect and Reflect • Conducted focus groups and interviews	• Foreign concept • Language barriers, varied understandings of ACP • People felt they didn't have the power or ability to make their own health care decisions • Cultural norms – ACP was not part of cultural norm • Death was a taboo subject • Religious beliefs portrayed ACP as unnatural • Practical barriers immigrants	• Large sample size • Diverse sample (wide age range and people that speak different languages) • Interviews and focus groups conducted in South Asian languages	• Not conducted by experienced researchers • Did not provide a framework for data analysis • Participants' time in Canada ranged from 2 to 38 years – large gap may result in different experiences, knowledge etc.

		(working, taking care of the family etc.) • Planning was associated with sorting out finances and possessions		
Con, A. 2007 Canada	• Qualitative study conducted with several ethnic minority groups within Canada • Participants: South Asian individuals from a South Asian's Women's Wellness Group • Key informants form across the country • Conducted 125 key informant interviews and 2 focus groups with people of South Asian heritage • Conducted content analysis	• Religious faith and belief that God was responsible for their illness and future deterred people from engaging in ACP • Unable to spend time with HCPs to discuss ACP • Other priorities in life	• Data source triangulation • Several types of key informants interviews (i.e. organizational, HCPS, ethnic/cultural) • Recruitment of key informants clear • Gathered key informants from across the nation – increases transferability • Focus groups in multiple languages	• Data collection methods unclear (i.e. unclear of who collected the data) • Inclusion exclusion criteria unclear
Doorenbos, A. Z. 2003 United States	• Descriptive correlational design • Recruited from Asian Indian community centre and mailing alumni of a university • Participants: 43 Asian Indian first-generation US immigrants older than 18 years of age • Data collected through surveys • Conducted	• 12% had knowledge hospice programs, 22% had little knowledge, 22% had no knowledge • 86% said that their choice of place of death would be the home • 88% of people said that their health care provider did not	• Efforts made to validate the survey • Survey development described well	• "Person-to-person" recruitment strategy unclear • Person-to-person recruitment may cause coercion • Data analysis not described well (i.e. what program was used, who completed the analysis and what statistical tests were run) • Description of results unclear • Response bias

	descriptive statistics and correlation	have end-of-life discussions with them • Positive correlation between time in the US and knowledge of hospice • Negative correlation between cultural-ethnic affiliation and hospice knowledge		• Respondents had high education level
Doorenbos, A. Z., & Nies, M. A. 2003 United States	• Descriptive exploratory study • Recruited in person or via mail from university, community and through the use of an alumni list from a school India, indicating the alumni that reside in the USA • Participants: Convenience sample of 45 Hindu Asian Indian immigrants • Data collected through surveys • Data analysis used bivariate and multivariate regression analysis and descriptive statistics	• 9% of respondents had living will • 0% had power of attorney • 44% have desire to complete • Negative correlation between religious faith/beliefs and completion of advance directives (stronger religious faith associated with less likelihood of completing advance directives) • Negative correlation with family involvement and advance directive completion • Positive	• Content and face validity achieved through the use of experts and pretesting • P value indicated • Results presented clearly using demographic data	• “Person-to-person” recruitment strategy unclear • Person-to-person recruitment may cause coercion • Self-report bias

		correlation with individualist decision making and advance directive completion		
Kristiansen, M., Irshad, T., Worth, A., Bhopal, R., Lawton, J., & Sheikh, A. 2014 Scotland	• Secondary analysis of longitudinal study • Recruited through health care and social care professionals in Scotland • Participants: 25 people (patients, family members and health care professionals) • Conducted 92 in-depth semi structured interviews in-home • Bereavement interviews conducted 8-12 weeks post-death • Used Mattingly's notion of hope as theoretical framework for analysis	• Hope was significantly important to their journey • Hope influenced the way in which they viewed their illness and created meaning of their experiences • Hope also influenced by social identity	• Provided demographic description of participants • Trilingual researcher	• Secondary analysis of data • Data collection unclear – recruited participants with approx. <1 year to live but followed participants for 18 months
Khosla, N., Washington, K. T., & Regunath, H. 2016 United States	• Multi-method qualitative descriptive study • Recruitment from 2 major health care systems • Participants: 57 health care providers • Purposive sampling • Conducted 23	• Health care providers found that South Asian patients were reluctant to use pain medications due to patient-related factors and factors related to the culture of care	• Multiple data collection methods • Data analysis conducted by two researchers using the Braun and Clarke framework • Diverse set of health care providers	• Inclusion-exclusion criteria not described • Participants in the study had little exposure to South Asian patients and had patients who were likely highly educated, influencing the validity of the

	Individual interviews and 4 focus groups which involved 35 participants	in South Asia • This is due to spiritual beliefs, lack of awareness and knowledge about the benefits of pain medications, concerns, different culturally influenced attitude towards pain medications		results
Khosla, N., Washington, K. T., Shaunfield, S., &Aslakson, R. 2017 United States	• Multi method qualitative descriptive study • Recruitment from 2 major health care systems • Participants: 57 participants (health care providers) • Purposive sampling • 23 Individual interviews and 4 focus groups which involved 35 participants • Conducted thematic analysis	• Health care professionals face several communication challenges • Ensuring effective interpretation • Identifying a spokesperson for the patient and understanding the family dynamics • Understanding cultural norms	• Multiple data collection methods • Data analysis conducted by two researchers using the Braun and Clarke framework • Diverse set of health care providers • Recruited South Asian physicians to provide personaland professional experience	• No framework used or mentioned for data analysis • South Asian health care providers in the study were all physicians
Owens, A., & Randhawa, G. 2004 United Kingdom	• Phenomenology study • Recruitment from community settings and hospice in Luton who work in palliative care settings • Participants: health care providers	• 5 themes that described the experience of health care providers caring for South Asians: definitions of palliative care, ideas of cultural difference,	• Good sample size • Data analysis involved use of framework	• No description of how the participants were recruited – i.e. the strategy used to obtain participants • The number of reviewers or authors involved in data collection and analysis unknown • No description of

	• 10 in-depth semi structured interviews • Coding technique guided by Denzin & Lincoln (1997)	South Asians' access to palliative care services, meeting the needs of South Asian patients, devising culturally competent care services • There is some tension between the different philosophies/definitions of palliative care • Can be difficult to reconcile philosophy of palliative care with cultural needs • HCPs try to understand the culture differences and acknowledge it in the provision of care • Cognisant of the impact of culture on communication and the importance of communication in providing quality care		demographic characteristics of participants
Radhakrishnan, K., Saxena, S., Jillapalli, R., Jang, Y., & Kim, M. 2017 United States	• Descriptive qualitative design • Recruitment from two senior citizen community-based organizations and word of mouth in	• 5 major themes: communication, time, space, social organization, environmental control and	• Detailed description of recruitment strategy for older South Asian Indian-American • Demographic data	• Unclear how the authors recruited family caregivers and physicians • No demographic data on physicians • Authors state the

	Texas • Participants: 36 older South Asian Indian-Americans, 10 South Asian Indian-American family caregivers, 4 South Asian Indian-American physicians • 11 focus groups conducted with older South Asian Indian Americans family care givers and physicians • Conducted in 3 different languages • English studies coded by 2 reviewers • Non-English transcripts were translated and coded by first authors, and cross-checked with a South Asian Indian-American community member	biological variation • Communication : physicians were hesitant to approach the conversation and South Asian patients expressed never having received ACP information but have expressed wishes informally • Time: a lack of time for patients to discuss ACP with HCPs • Space: where they received ACP information and the people who are present affected readiness to discuss ACP and end of life • Social organization: cultural perspectives on death and dying and idea of filial piety deterred people from speaking about ACP and end of life openly • Environmental control: people with less financial and other resources	of participants provided of family members and older adults • Cross checked translations	transcripts were cross-checked but unclear of the process and whether member checking was completed

		more inclined to talk about ACP and end of life • Biological variation: people who valued quality of life over longevity more inclined to talk about ACP		
Randhawa, G., Owens, A., Fitches, R., & Khan, Z. 2003 United Kingdom	• Exploratory study • Participants: service providers and service users of palliative care services • Semi-structured interviews with 12 adults from 5 families • 10 interviews with service providers • Coding technique guided by O'Brien (1993)	• Communication was a significant challenge and barrier for patients and families (ex: language barriers) • Service providers express similar challenges with communication and felt that existing strategies were ineffective • Overall, communication between South Asian patients and service providers faces several challenges and needs improvement	• Use of coding technique to guide data analysis •	• Little information regarding participant demographics • Unclear how the interview process occurred • Number of reviews and authors involved in data collection and analysis not described
Sharma, R. K., Khosla, N., Tulsky, J. A., & Carrese, J. A. 2012	• Focus group study • Recruited participants from university campus and South Asian religious, cultural	• Sense of familial duty among first and second generations • Acculturation	• Clear inclusion-exclusion criteria • Two investigators involved in data analysis and collection	• Weak methodology and no clear methodological framework • Only English focus groups

United States	and professional organizations through posters • Participants:12 first generation and 11 second generation South Asian • A total of 4 focus groups conducted • Content analysis of focus groups	did not equate to rejection of traditional beliefs • Sense of familial duty and reciprocity negatively affected person's ability to communicate end-of-life wishes	• Demographic information presented of each focus group	• First and second generation appear to be in the same focus groups- this can influence participants' responses
Somerville, J. 2001 United Kingdom	• Qualitative exploratory study • Participants: 7 bereaved Bangladeshi caregivers • Semi-structured interviews • Data analysis using Burnard's method (1991)	• 4 main themes: caring, support, communication and home and family • Caregivers experienced challenges and barriers related to the 4 themes, as well as communication barriers, isolation, anxiety	• Female interpreters used with female participants to enable comfort during the interview process and enable rich data • Interpreter available • Bereavement period of 2-12 months • Two reviewers for data analysis	• Small sample size • Member checked with only 1 participant • Use of interpretation can hinder data collection and analysis
Spruyt, O. 1999 England	• Unspecified study design • Recruited from borough of Tower Hamlets in UK • Recruitment completed with Bengali and English letters and recruiting a Bangladeshi male interviewer to call participants and explain the study • Participants: 18 Bangladeshi bereaved primary carers	• Communication challenges faced by caregivers • Perceived pain control to be inadequate in some cases • Most of their support came from family and friends • Practical help required (i.e. equipment, finances, transportation)	• Demographic information provided clearly • Clear aim of the study •	• Data collection strategy of manually recording interviews unclear • Researchers did not tape interviews and then transcribe, resulting in the possibility of inaccurate results • Bereaved participants had long periods of bereavement, resulting in recall bias • Data analysis strategy or

	• Semi structure interviews in Sylheti • Data analysis not described			framework not described
Venkatasalu, M. R., Arthur, A., & Seymour, J. 2013 England	• Constructivist grounded theory approach • Recruited from 11 community organizations in East London • Participants: 55 South Asians • Conducted 5 focus groups and 29 in-depth interviews • Data analysis followed Charmaz's grounded theory methods	• 2 major themes • Participants avoided talking about death as a cultural norm • Participants felt that talking about death would cause distress among family, and decision-making power was handed to family	• Large sample size • Males and females included • Participants of different South Asians sub-groups included • Collected data in different languages • Data collection and analysis described well	• Interview's characteristics may influenced the relationship with the participant and ability of participant to contribute freely and unbiased • Number of participants in focus groups unclear • Description or definition of "community organization" not identified • Some demographic information about participants missing, reducing transferability
Venkatasalu, M. R., Seymour, J. E., & Arthur, A. 2014 England	• Constructivist grounded theory approach • Recruited from 11 community organizations in East London • Participants: 55 South Asians • Conducted 5 focus groups and 29 in-depth interviews • Data analysis followed Charmaz's grounded theory methods	• 2 major themes: reconsidering the homeland and home as haven • Participants felt that being able to carry out their cultural and religious practices was more important that the physical place of death • Felt that returning to homeland would be ideal but challenging	• Clear inclusion criteria • Recruitment process well described • Data analysis and management described well	• Interview's characteristics may influenced the relationship with the participant and ability of participant to contribute freely and unbiased • Number of participants in focus groups unclear • Description or definition of "community organization" not identified • Some demographic information about participants missing, reducing

				transferability
Weerasinghe, S., & Maddalena, V. 2016 Canada	• Qualitative study • Recruited through South Asian community associations • Participants: 7 bereaved South Asian caregivers • Conducted one-on-one interviews with • Data analyzed using grounded theory coding methods	• 3 major themes • Clash between South Asian culture and culture of care in Canada • Family members were mediators during the care process • Communication challenges faced	• 2 researchers coded independently and compared • Aim of study clear • Mixture of participants from different South Asian sub-groups	• Unclear data analysis strategy • Unclear methodological approach • Small sample size • Mostly male participants • No clear demographic description of participants • Participant sample fairly homogenous sample (i.e. all married, mostly men, not living with children, elderly)
Wilkinson E., Randhawa G., Brown E., Da Silva Gane M., Stoves J., Warwick G., Akhtar, T., Magee, R., Sharman, S. & Farrington, K. 2016 United Kingdom	• Action research methodology • Recruited through the principle investigator • Participants:16 patients and 45 care providers • Conducted interviews with 16 participants and focus groups with care providers • Data analysed by lead researcher through thematic analysis	• Care providers had trouble identifying when patients are reaching end of life • Have different definitions of end of life • Lack of awareness among patients for need for end of life or what end of life meant • Communication with patients and family members about end of life care largely affected by family members' willingness to have these conversations	• Large sample size • Data source triangulation • Interviews in multiple languages conducted by multiple bilingual interviewers • Interviewers trained to enhance trustworthiness	• Recruitment methods unclear • Only one investigator conducted data analysis • No member checking •

		(family members less willing) • Differences in nursing cultures with kidney care services affected approaches to end of life care • Other factors that inhibited end of life care conversations included lack of time and lack of confidence		
Worth A., Irshad T., Bhopal R., Brown D., Lawton J., Grant E., Murray S., Kendall M., Adam J., Gardee, R. & Sheikh, A. 2009 Scotland	• Prospective longitudinal qualitative design • Recruited through HCPs, volunteers and community and religious leaders • Purposive sampling • Participants: 25 South Asian Sikh and Muslim people, 18 carers and 20 HCPs • Conducted in-depth semi structured interviews • 92 interviews in total over 18 months	• Cultural barriers and lack of understanding of palliative care among South Asian patients • Lack of cultural understanding, institutional discrimination and interpretation were seen as barriers among HCPs providing care	• Recruitment and interviews done in multiple languages • Large sample size • Data source triangulation	• Recruitment methods not described clearly • Date analysis not described well – no framework applied • Lack of sufficient demographic data on participants • Unclear inclusion-exclusion criteria

Appendix E

Ethics Approval

HiREB
Hamilton Integrated Research Ethics Board

October 11 2017

Project Number:3896

Project Title: The Experience of Bereaved South Asian Informal Caregivers of Adults Family Members or Loved Ones in Their Last Year of Life: An InterpretiveDescription

Student Principal Investigator: Miss Pereyanga Kulasegaram

Local Principal Investigator: Dr. Sharon Kaasalainen

We have completed our review of your study and are please to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Consent Form for Participants - Version 2	Sep-26-2017	2
Consent Form for Translators	Aug-30-2017	1
Data Collection Sheet - Version 1	Sep-26-2017	1
Demographic Form - Version 2	Sep-26-2017	2
MScN Thesis - Research Protocol - Version 2	Oct-02-2017	2
MScN Thesis Study Budget - Version 2	Oct-02-2017	2
Participant Contact Information - Version 1	Sep-26-2017	1
Recruitment Email Script for Student Researcher - Version 2	Sep-26-2017	2
Recruitment Postcard - Version 2	Sep-26-2017	2
Recruitment Telephone Script for Recruitment Partners - Version 2	Sep-26-2017	2
Recruitment Telephone Script for Student Researcher - Version 2	Sep-26-2017	2

We acknowledge the following documents:

Scarborough Centre for Healthy Communities - Emails Confirming Partnership - Oct-02-2017 Version 2

Heart Hospice - Emails Confirming Partnership - Oct-02-2017 Version 2

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**.
If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University