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The Experiences of End-of-Life In-home Caregiving by Immigrant Family Caregivers

Gana, Rhodric

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The Experiences of End-of-Life In-home Caregiving by Immigrant Family Caregivers

by

Rhodric Samgwa Gana

A THESIS

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Abstract

The de-institutionalization of healthcare systems around the world has led to the rise of home care services as a preferred option. Many people with life limiting illnesses have expressed their wish to stay at home during End-of-Life (EOL) care. The ability to die at home is made possible partly by significant levels of informal caregiving from family members and friends. In-home caregiving presents many positive and negative experiences that are common among Canadian family caregivers and their loved ones. However, cultural values and norms for immigrant family caregivers may shape the experience of in-home caregiving in unexpected ways. The purpose of this research is to understand the immigrant family caregiver's experience of End-of-Life in-home caregiving. Using a Constructivist Grounded Theory methodology, I interviewed immigrant family caregivers who described their experience of taking care of a loved one dying at home. Semi-structured interviews with guided questions were the means by which seven immigrant family caregivers described their experience of EOL in-home caregiving. I analyzed the data using coding, memo-writing, theoretical sampling, and constant-comparative processes. This analysis led to the co-construction of the theory *Immigrant family caregiver experience of EOL in-home caregiving: A Relational Process of Maintaining Dignity in Dying*. Encompassed within this theory are three interrelated categories and nine sub-categories.

Keywords: Immigrant, informal caregiving, in-home caregiving, End-of-Life, constructivist grounded theory.

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Dedication

I dedicate this thesis to all the family caregivers who are doing the work of God. Your work is unpaid and sometimes unacknowledged or unappreciated. Your dedication to your loved one remains an inspiration to me.

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List of Symbols, Abbreviations, Nomenclature

Age-Standardized Mortality Rate (ASMR)

Alberta Health Services (AHS)

Canadian Hospice Palliative Care Association (CHPCA)

Canadian Institute for Health Information (CIHI)

Goals of Care Designation (GCD)

Conjoint Health Research Ethic Board (CHREB)

Constructivist Grounded Theory (CGT)

Grounded Theory (GT)

End-of-Life (EOL)

Health Care Provider (HCP)

Healthy Immigrant Effect (HIE)

Home Care (HC)

Immigration, Refugees and Citizenship Canada (IRCC)

Palliative Home Care (PHC)

Palliative Care Early and Systematic (PaCES)

Quality of Life (QOL)

Social Determinants of Health (SDH)

Chapter One: Introduction

Throughout history, caregiving has occurred within the family structure with family caregivers (FCGs) playing a vital role in the well-being of a loved one. Families are the most prevalent caregivers to dying persons worldwide (Emanuel et al., 2000). FCGs are a pivotal source of support for quality of life, well-being, and quality of care for terminally ill patients (Ullrich et al., 2017). At end-of-life (EOL), FCGs often confront some of the most stressful experiences in caregiving and may thus be affected by significant physical and psychosocial burden. This may include exhaustion and sleep disturbances for FCGs of home cared terminally ill patients (Corà et al., 2012), emotional problems such as helplessness, uncertainty, and hopelessness (Robinson et al., 2014), substantial reorganization or disruption of the family system, and increased possibilities for family conflict (Kramer et al., 2006), financial problems, isolation, and occupation-related problems in the phase of caregiving (Hudson et al., 2011), or the need to act as the patient's surrogate on decisions such as use of life-sustaining treatments (Hebert & Schulz, 2008). Commonly referred to as 'hidden patients' (Kristjanson & Aoun, 2004), these FCGs experience caregiver burdens that may not be obvious especially in an independent setting like at home. Patients and FCGs staying at home for EOL face burdens in addition to managing complex care needs – they have to navigate home care systems, make legal arrangements, and cope with grief (Apatira et al., 2008). Despite the availability of home care support in most Canadian communities, the ability to die in this patients' preferred setting requires a great deal of support from family members.

According to a Statistics Canada (2012) General Social Survey on EOL, 35% of Canadians who had provided care for their terminally ill relative or friend did so at home and for those who did not provide care in their own home, 17% would have preferred this option (EOL at home). This survey corroborates the preference of many Canadians to die at home and is suggestive of a critical

collaborative relationship between FCGs and professional services for an optimal home death experience. Seow and Bainbridge (2018) reported that without professional support, dying at home is not feasible because of how intense and complex EOL care can be. For many FCGs, informal caregiving is complemented by professional support which provides vital assistance and caregiver relief without which in-home caregiving could be more challenging. EOL care at home is important because it can be high quality, personalized, and more cost-effective than care in hospitals (Canadian Institute for Health Information [CIHI], 2007; Canadian Hospice Palliative Care Association [CHPCA] 2013, 2015; Higginson & Evans, 2010). While the importance of informal caregiving cannot not be neglected for EOL in-home caregiving, the role of formal palliative care support services cannot be underestimated. The two frequently blend together well for an optimal EOL experience for both FCGs and their loved ones. In their study, Dhiliwal and Muckaden (2015) identified multiple benefits of a specialized formal support for the patient and FCG at home, listing improvements in symptom control, health-related communication, psychosocial support, appropriate and early hospice referral, and averted needless hospitalization; improved bereavement outcomes and caregiver satisfaction. In general, professional palliative care support is focused on quality of life for a patient and their family by managing symptoms, and providing emotional and psychological support. In Alberta, the provision of formal EOL care at home is the primary responsibility of Palliative Home care (PHC) service, a department in Alberta Health Services (AHS). PHC is responsible for the provision of in-home care, support, and comfort to people coming to the end of their lives and their families while supporting informal EOL in-home caregiving. In Alberta, AHS delivers PHC services across the province with 6,912 clients in 2018 (Johnson et al., 2018). Between 2016 and 2017, 47% of home care clients in Alberta received professional support in the last year of life (Canadian Institute of Health Information [CIHI], 2018). The Calgary Zone is one of the five geographically administrative zones in the province,

providing professional EOL services to over 1.5 million people and a size of 39,300 km². The PHC program in Calgary Zone provides 24-hour access so that patients and families can receive support for symptom management, emotional, and psychological support at EOL (AHS, 2014).

According to Statistics (2016), an immigrant refers to a person who is, or who has ever been a landed immigrant or permanent resident. Through the process of immigration, immigrants are integrated as part of the a new society, a new country and a new experience. In Canada, such a person has been granted the right to live permanently by immigration authorities – Immigration, Refugees and Citizenship Canada (IRCC). The IRCC facilitates the arrival of immigrants, provides protection to refugees, and offers programming to help newcomers settle in Canada (Government of Canada, 2021). In this study, the term *immigrant* was expansive – it included all who had move to Canada regardless of the year of their immigration or how they became a landed immigrant. This was because the simplicity of this definition facilitated participant recruitment without imposing any limitations based on conditions.

The ongoing influx of immigrants to Canada means that they (immigrants) represent a significant subset of FCGs providing informal support at home for a terminally ill relative. This is evident as described in a recent study that showed that more than 286,000 new permanent residents in Canada existed in 2017 (Meissner & Vertovec, 2015), with admissions projected to reach 350,000 in 2021 (Immigration, Refugees and Citizenship Canada [IRCC], 2018). Also, 21.9% of the Canadian population identify as having been landed immigrants or permanent residents in a 2016 census (Statistics Canada, 2017). Although challenges exist for any FCG, EOL in-home caregiving presents additional nuanced challenges and experiences for immigrants FCGs than for native-born Canadians especially considering the various service barriers that culturally diverse FCGs face (Scharlach et al., 2006). Such barriers include: language incompetency, insufficient social support, and limited health

service access and utilization (Olson, 2001). In addition to these factors, Omariba and Ng (2011) identified a limited health literacy (ability to access and use health information to make appropriate health decisions and maintain basic health) while Burgess (2004) identified cross-cultural communication, disparate health practice beliefs, and limited cultural awareness on the part of the provider as other major factors influencing access to health services as well as health outcomes on immigrants. These factors suggest significant variations in post-migration health across immigrant FCGs considering their different backgrounds as they support patients at EOL at home.

Problem Statement

AHS patients reflect the more general statistics about preferred location of death and FCG roles, with a sizable portion of the patient population made up of immigrants who as in other jurisdictions face additional complexities in caring for loved ones dying at home. For many patients and FCGs experiencing life-limiting conditions, home-based EOL care is common and indeed preferred. This trend is potentially similar for immigrant patients and FCGs but with additional complexities as a result of the barriers already faced by this particular population. Immigrants (see definition below) to Canada tend to arrive healthier than people who are Canadian-born but over time as their years in Canada increase, their health deteriorates; this has been termed the “healthy immigrant effect (HIE)” (Asanin, & Wilson, 2008; Ng, 2011; Vang et al., 2017). Despite the HIE, some immigrants will subsequently experience excess morbidity and mortality from some chronic medical and psychiatric conditions (Fuller-Thomson et al., 2011) potentially receiving a home support from an immigrant relative as an informal FCG for EOL.

In situations where immigrant FCGs are confronted with home-based EOL care of a relative in Alberta, they may face cultural and logistical challenges due to decreased health literacy or language ability, different modes of family based decision-making and filial responsibility, and decreased access

to care due to insufficient financial and social resources (Bosma et al., 2010; Cruz-Oliver et al., 2014; Unroe et al., 2012). Poor proficiency in English or French (depending on the country of origin), age of arrival (65 and above), and recency of arrival in Canada significantly predicts a limited health literacy among immigrants (Omariba & Ng, 2011). Thus, information access and utilization in palliative care services can be challenging for this population. Considering these challenges, Seto and Angus (2012) said that immigrants have to negotiate death with professional support similar to the journeys that has taken them from one home to another in new countries. Like moving to and adapting to a new country, immigrants FCGs have to rely on accumulated knowledge, experiences, and assumptions to understand and navigate EOL in-home caregiving in Canada. The similarity is in the unfamiliarity of both experiences as the immigrant might need support in order to navigate challenges. Care recipients and their immigrant family caregivers have to negotiate care with palliative care professionals and other informal caregivers in ways that accommodate their cultural values. This makes a culturally appropriate approach to EOL in-home caregiving beneficial (Benzar et al., 2011). Nonetheless, this approach is challenged by a lack of research in examining the actual process of how immigrant FCGs (considering all the complexities of integration) experience EOL in-home caregiving in Canada in general and Alberta in particular to the best of my knowledge. This study sets out to provide insight into these existing knowledge gaps by exploring the in-home caregiving experiences of immigrant FCGs supporting a terminally ill loved one at home.

Definitions

For the purpose of this study, the term immigrant is any person from another country who has legal status to reside in Canada either as an *Economic Class* immigrant which is a category of immigrants selected for their skills and ability to contribute to Canada's economy (skilled workers, provincial and territorial nominees, business immigrants, Quebec skilled workers and Canadian

Experience Class members, and their spouses and dependents (IRCC, 2018) or *Family Class* immigrant which is an immigration category that includes any family members sponsored to come to Canada by a Canadian citizen or permanent resident (IRCC, 2018).

Palliative Care – World Health Organization (WHO) defines palliative care as an “approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2019).

Palliative Home Care – Palliative care, support, and comfort to people coming to the end of their lives and their families with a focus on managing symptom issues, providing emotional and psychological support at home (AHS, 2019).

End-of-life (EOL) care refers to care for people in decline who are considered to have a terminal disease or dying in the foreseeable (near) future (CIHI, 2011).

The term EOL and palliative care are often used interchangeably but mean two different things. Palliative care focuses on pain relief and control of symptoms and to improve the quality of care for patients. According to Van Mechelen et al. (2013), some HCPs, lay people, and even research studies have used the term palliative care synonymous to EOL care – a situation that has created confusion regarding the exact content of the various concepts, the stage of life to which these concepts refer, and the patients for whom they may be appropriate. EOL care is defined by the Canadian Institute for Health Information (CIHI) as care for people in decline who are considered to have to be terminal disease or dying in the foreseeable (near) future (CIHI, 2011). In practice, the diversity of the palliative and EOL patient population may result in ambiguity when describing these patients.

Purpose of Study

The purpose of this qualitative study is to understand the in-home caregiving experiences of immigrant FCGs as they support a terminally ill relative in Calgary Zone, Alberta. A Constructivist Grounded Theory (CGT) (Charmaz, 2014) qualitative methodology will be used and will allow for a partnership between the researcher and participants in order to explore the multiple realities of EOL in-home caregiving among immigrant populations.

Research Question

In response to the study purpose, the following research question (RQ) emerged:

What are the EOL in-home caregiving experiences of immigrant family caregivers?

Researcher's Assumptions

This study proposes that as immigrant FCGs provide EOL in-home caregiving to a terminally loved one, they will experience alterations in the meaning of a home, health, cultural values, and traditions. The basis of my assumptions stems from the beginning of my career as a nurse internationally in 2009 before moving to Canada in 2012 and then becoming a Registered Nurse in 2015. In Alberta, my work predominantly involves working with older adults and their family caregivers. Throughout my career, I have been intrigued by the commitments and contributions of family caregivers to support the quality of life (QOL) of their loved ones. This has made me appreciate firsthand the benefits and the challenges of being a family caregiver. As an immigrant myself, I have often pondered what this experience is like for family caregivers still adapting to a new country while providing informal care to a dying loved one. I am curious to know what the EOL in-home caregiving experience could be for immigrant family caregivers and their loved ones, and I was prompted to further explore the topics of immigration, EOL, and in-home caregiving. I approached this study with the assumption that the experience of EOL caregiving at home by immigrant FCGs may be

compounded by factors related to immigration and adaptation not obvious to native-born Canadians. This assumption is significant when FCGs have to interact with an unfamiliar health care system and particularly so when the patient is receiving EOL care at home. I presuppose that the barriers already faced by immigrant FCGs will make EOL in-home caregiving in Alberta even more challenging than that of the average native born-Canadian.

Study Significance/Rationale

The study's timing is significant because it takes into account the historical push for the de-institutionalization of the health care system, making in-home caregiving a viable option for End-of-Life (EOL) among many Canadians. While home-based palliative care is associated with higher levels of patient and FCG satisfaction (Dhiliwal et al., 2015), many FCGs who assume the caregiver role become vulnerable to personal economic hardship and financial stress, as well as the fallout from such stress resulting in poorer health (National Alliance for Caregiving & Evercare, 2009; National Family Caregiving Association, 2009). Consequently, the need for a research study to understand how immigrant FCG experience EOL in-home caregiving. This is significant because it can provide valuable data on how palliative care professionals can better understand and support immigrant FCGs providing informal caregiving to a terminally ill loved one at home. This research will also be a platform for future research work on the implications of EOL in-home caregiving for immigrant populations.

Outline of Chapters

For readability and a chronological flow of information, this thesis is organized into the following chapters: introduction, literature review, methodology, data analysis, and discussion. Each section throughout the thesis will provide insightful and engaging information to support conducting the research project and the overall findings.

In the second chapter of this thesis, I present a review of the literature that explores and relates to the gap of immigrants experiencing EOL in-home caregiving in the Calgary Zone, Alberta. The purpose of completing a thorough literature review is to provide context to the research study. Furthermore, the literature review informs the researcher on the current studies completed about this topic, critical for finding where the study fits within the context of existing research.

In the third chapter of this thesis, I will give an overview of the history of Grounded Theory, the underpinnings and tenets of Constructivist grounded theory (CGT); the methods used in my study, as well as explain my data collection strategy which includes sampling, participant recruitment, interviews, coding, memo writing – all integral to CGT theory. Also, I will describe how CGT is an appropriate methodology to answer my research aims. I will discuss issues of trustworthiness, and ethical considerations. For the remaining chapters, the fourth chapter will be on results of the study, while the fifth chapter discusses the results compared to the existing empirical literature and provides implications for practice and further research.

Summary

The introduction provided an overview of the reasons for completing the research project, which included: background to the study, problem statement, definitions, purpose of study, research question, researcher assumptions, and study significance and rationale, concluding with the organization of the thesis. This study aims to contribute to existing literature regarding how immigrant FCGs' experiences shape the ways in which they support a dying loved one at home. Ideally, this research will present a small piece of evidence that shows how this experience may be different for immigrant FCGs and native born Canadians. Although this research has been conducted in Calgary, Alberta, it has the potential to add to the understanding of experiences of most immigrant FCGs as it relates to EOL caregiving nationwide. The next chapter will present an in-depth literature review.

Chapter Two: Literature Review

Canada is a multi-ethnic and multicultural nation with ongoing immigration continually adding to this diversity. This diversity is central to the identity of Canada and what it means to be Canadian. The words ethnicity and culture have significant overlap and are usually used interchangeably although they mean different things; ethnicity primarily refers to group identity arising from a common history, kinship and language while culture refers to the way members of a particular ethnic group relate to their environment and each other (Merriam Webster, n.d). With significant levels and diversity of immigrants, the Immigration, Refugees and Citizenship Canada (IRCC) have numerous projects to support newcomers' settlement and social integration. Through the IRCC's Settlement Program, eligible newcomers (immigrants and refugees) receive information about life in Canada and the community in which they will settle, language training, help finding a job, and connections with established immigrants and Canadians (Government of Canada, 2019). Despite these supports, immigrant integration and adaptation are still hindered by numerous challenges. Such challenges include health care access barriers, language barriers, cultural beliefs, and lack of support (Olson, 2001; Omariba & Ng, 2011). Considering these challenges and with particular attention to the focus of this study, it is imperative that immigrant FCGs guide EOL in-home caregiving and ensure that the formal care received is culturally sensitive – care that is relevant to patients' needs and expectations (Majumdar et al., 2004). Culturally sensitive EOL care is valuable because it involves the integration of cultural knowledge and awareness into individual and institutional behavior (Wells, 2000). It allows palliative care professionals to understand, respect, and consider the particular cultures their patients and their families come from. For example, it is considered inappropriate and culturally insensitive to discuss impending death with patients and families in some cultures while other cultures are willing to engage in such conversations.

A few studies have explored the experiences of migration and post-immigration resettlement on palliative care among immigrant FCGs with specific attention to Chinese immigrants (Seto & Angus, 2012; Nielsen et al., 2015 in Ontario and Nova Scotia respectively). Seto and Angus (2012) concluded that a key implication is the need to move away from simplistic conceptualizations of culture to a critical approach that will enable HCPs to understand and find comfort in working with the fluid, dynamic, and contextually-driven nature of culture and dying at home. Nielsen et al. (2015) supported this by highlighting the need for cultural competence to move away from models that portray cultural beliefs as shared, fixed patterns, and take into account the complicated reality of everyday care provision with respect to EOL in the home. These two studies highlighted culture as a broad and ever-changing attribute that has significant influence of how to support a dying loved one at home. Klassen et al. (2012) conducted a study in six pediatric oncology facilities on immigrant parents dealing with pediatric cancers (malignancy) supported the need for education to ensure that HCPs develop cultural awareness, knowledge, attitudes, and communication skills. In general, the conclusions supported the idea that EOL in-home caregiving experiences among immigrants are complex, requiring HCPs' awareness and responsiveness to the diversity in the immigrant populations, and the cultural influence on death and dying at home in a new health care system. Additionally, the heterogeneity of immigrant FCGs and their loved ones make the provision of culturally sensitive and competent EOL care a challenge for palliative care professionals (Ahmed, Shommu et., 2016). I intend to synthesize the literature on these concepts.

Immigrants, Immigration, and Canada

In 2017, the majorities (60.3%) of new immigrants were admitted under the economic category, 26.8% were admitted under the family class to join family already in the country, and 11.6% were admitted to Canada as refugees (Statistics Canada, 2017). For the first time, Africa ranked second

ahead of Europe as a source continent of recent immigrants to Canada, with a share of 13.4% in 2016 while Asia (including the Middle East) remains the top source continent of recent immigrants with the majority (61.8%) (Statistics Canada, 2017). Toronto, Vancouver, and Montreal are still the place of residence of many immigrants to Canada. In addition to contributing to the social and economic development of the country, immigrants and their descendants play a significant role in shaping and enriching the ethnic, cultural, and linguistic composition of Canadian society. Among recent immigrants living in Canada in 2016, almost half (48.0%) economic immigrants were admitted through the skilled workers program and more than a quarter (27.3%) under the provincial and territorial nominees' program (Statistics Canada, 2017). The increase in the number and diversity of international immigration to western developed countries has raised public and policy concerns about how well immigrants will be integrated into the economic and social fabric of the receiving society (Hou et al, 2018). These concerns are accentuated because immigration generally includes a series of transitions: changes in personal ties and the reconstruction of social networks, the move from one socio-economic system to another, and a change from one cultural system to another. New immigrants to Canada have to adapt and integrate into an unfamiliar environment and the dominant Canadian culture. While there are challenges immigrants face with integration, immigrating to Canada offers immigrants a chance at a better life with better economic opportunities and safety than their countries of origin.

Despite the heterogeneous nature of immigrant populations, there are similarities in the challenges associated with integration and adaptation in the new host country. The process of adaptation is best described as acculturation. Acculturation is broadly defined as the set of cultural and psychological changes that follow the contact between two cultural groups and their members (Berry, 2005). For many, it begins immediately post-immigration and is potentially long and challenging. Historically, acculturation as an immigrant experience was frequently viewed as a unidirectional

process of assimilation with immigrants adopting the dominant culture to the detriment of their traditional customs. Gordon (1964) argued that for newcomers, "the price of such assimilation is the disappearance of the ethnic group as a separate entity and the evaporation of its distinctive values" (p. 81). This argument views acculturation as a natural and evolutionary process where minority groups had to adjust to the mainstream culture. Conversely, later perceptions of immigrant acculturation led to a bi-dimensional approach, an acknowledgment that immigrants can identify with both their previous culture and the dominant culture of the new host country (Bourhis et al., 1997). A large body of psychological and sociological research supports the bi-dimensional approach underlying immigrants' sociocultural and psychological integration: cultural maintenance (the importance of retaining own-group heritage culture) and participation in the receiving society (Berry, 1997; Ward 2013). This implies that immigrants still held on to their traditional sub-identities while gaining membership into the new host society.

Berry (1980), a cultural psychologist developed a model, with two dimensions (previous culture and dominant culture) intersecting to create four acculturation categories — assimilation (adopts the receiving culture and discards the heritage culture), separation (rejects the receiving culture and retains the heritage culture), integration (adopts the receiving culture and retains the heritage culture), and marginalization (rejects both the heritage and receiving cultures). These acculturation categories have been widely used to understand immigrant integration in a new society with the integrated acculturation strategy being associated with the most favorable psychosocial outcomes, especially among young immigrants (David et al., 2009). Such outcomes include higher self-esteem, lower depression, and pro-social behaviors (Chen et al., 2008). With the integrated acculturation strategy, immigrants embrace both cultures; placing value on original cultural identity to guide contact with the new environment in order to guarantee a successful merger with the values of the dominant society. This acculturation

model has also come under some criticism itself. Rudmin (2003) criticized Berry's model because the categories were not well differentiated, the categories required the classification of individuals as high or low on receiving-culture acquisition and on heritage-culture retention; that it adopts a "one size fits all" approach for all immigrants. Another criticism of the Berry model was the notion of validity of marginalization as an approach to acculturation (Del Pilar & Udasco, 2004) — the likelihood that a person will develop a cultural sense of self without drawing on either their heritage or receiving cultural contexts (Schwartz et al., 2010). The unidirectional or bi-dimensional views are not set rules for acculturation and are not mutually exclusive to each other. An immigrant's acculturation experience often is not systematic but a complex interactive process with lots of positive and negative events and feelings. Post-migration resettlement and integration unfolds not as an isolated process but a continuous and interactive break down in social barriers to participation in the larger society, and promoting opportunities for intercultural encounters in person, in the media, in schools, and in other institutions (Berry & Hou, 2016). Acculturation for the recent immigrant becomes a serious question of (1) is it of value to maintain the original cultural heritage? And (2) is it of value to engage in intercultural contact with other groups, including members of the dominant culture? (Berry, 1997). For the immigrant family, this could take any form depending on internal familial characteristics and the external dominant cultural characteristics.

Immigration as a Social Determinant of Health

The health of immigrants is a product of environmental, economic, genetic, and socio-cultural factors related to when they immigrated to Canada, where and how they lived previously, and how and why they immigrated (Gushulak et al., 2011). The interactions of pre-migration, migration, and post-migration experiences have substantial bearing on the social determinants of health (SDH) of many immigrants. For Castaeda et al. (2015), the immigration experience itself must also be positioned as a

SDH in its own right. This argument relies on the notion that pre-migration social and environmental factors can intersect with the post-migration adaptive strategies in ways that affect the health of immigrants. Access to healthcare is a documented SDH for immigrants with limitations due to barriers such as poor understanding of health care systems, linguistic barriers, cultural barriers, discrimination issues, and economic barriers (Setia et al., 2011). Even when health care is accessed, there may be some crucial societal and cultural dimensions of immigrants that exerts significant influences on the understanding, recognition and management of health among this population.

Post-immigration factors such as place of residence, employment, education, income, and access to healthcare can also influence the health of immigrants (Gushulak et al., 2011). One of such is the difficulty immigrants have in navigating the health care system due to lack of knowledge about available resources, insufficient language appropriate health material, and limited personal financial resources (Betancourt et al., 2003; Daker et al., 2002; Lampley-Dallas, 2002). Barriers such as these have a detrimental impact on the use of formal supports by ethnically diverse immigrant family caregivers (Daker-White et al., 2002). Scheppers et al. (2006), in their review suggest that potential barriers occur at three levels: individual, HCP, and system levels. At the individual level, characteristics were identified as demographic variables, social support variables, health beliefs and values, personal and community enabling resources, and perceived personal health practices. At the provider level, attitudes and skills of the HCP were reported as potential barriers while at the system level barriers were associated with the organization of the health care system. Lai and Chau (2007) revealed that service barriers were predictive of adverse outcomes for elderly immigrants in regards to their physical and mental health. One proposed mechanism to overcome these barriers is cultural competence training on the part of HCPs and organizations to reduce racial and ethnic disparities in care (Weech-Maldonado et al., 2012) as it recognizes the importance of social and cultural influences on patients considering

how these factors interact, and devising interventions that take these issues into account (Betancourt et al., 2003).

Conversely, many studies have reported the "Healthy Immigrant Effect (HIE)" (Asanin, & Wilson, 2008; Ng, 2011; Vang et al., 2017) arguing that the general health of immigrants is significantly better than native-born Canadians immediately after immigration. This argument appears to be based on pre-immigration cultural and health practices in combination with the rigorous selective processes of the immigration. However, HIE advantage is lost over time; a phenomenon called the convergence paradigm of acculturation (Gushulak & MacPherson, 2006; Ng, 2015). This is different for each immigrant and dependent on their immigration status (economic class, family class and refugees) support systems, health status, length of stay in Canada, income among others. Ahmed et al. (2016) reported causal factors for this deterioration in health status to include discrimination, cultural differences, environmental factors, and health care system-related factors.

The SDH lens on immigration highlights two prominent limitations; “firstly, the diversity of countries and immigrant groups data are not easily comparable, and secondly, the generalization of results received in one context and for another context may be questioned” (Titzmann & Fuligni, 2015. p.409). This makes it challenging in discussing the differences and similarities across related studies. Consequently, though access to healthcare has the potential to improve with more awareness of available services, the specificity of immigrants attributes and the heterogeneity of this population’s experiences, and contexts made it challenging to assess the impact of SDHs.

Implications of Immigration on Health Care Providers

The diversity and differences in health determinants, migration experiences, language, and culture among migrant patients can be pose challenges for HCPs and health care systems. This diversity may be highlighted in the urban metropolitan areas of provinces where most immigrants

particularly recent immigrants reside in Canada (Statistics Canada, 2016). This diversity suggests that while HCPs in situations involving small numbers or groups of immigrants can benefit from standardized guidelines and recommendations, aggregate or collaborative studies on the subject may be hard to do. It is important for HCPs to know the value of understanding patients' beliefs, behaviors, and values in order to deliver care in a culturally competent and culturally safe manner. Community and public health initiatives involving national coordination of multiple centers and standardized definitions can provide improved understanding of migration-associated health issues and reduce cohort effects (Gushulak et al., 2011). For example, Canada's Tuberculosis (TB) surveillance system has relied on the chest radiography to i) identify persons with prevalent active TB pre-arrival and ii) identify persons at risk of developing and transmitting TB post arrival (Chan et al., 2017). Applicants with a history of treated TB or evidence of old healed TB on pre-arrival chest radiography undergo follow-up with public health authorities after arrival. HCPs have to be aware of countries at high risk of infectious diseases such as TB to better serve immigrant populations.

Considering the immigrant populations, HCPs and health care systems should be vigilant in looking for infections or diseases among newcomers from particular regions of the world with high prevalence of health conditions of concern. This is particularly significant for communicable diseases not prevalent in Canada. This has implications on how HCPs obtain health histories from immigrant patients to help determine their health risks and suitable next steps in patient care. HCPs ought to be ready to help new immigrants with health conditions to identify and share community health supports that may assist immigrants and refugees. To effectively support immigrants, HCPs and health systems have to keep in mind the immigrants' life experiences and transitions when planning and providing care.

Family (Informal) Caregiver

FCG(s) is a family member(s) who assumes the informal caregiving role, providing significant contribution to care (Aoun et al., 2005) as an unpaid non-professional (Navaie-Waliser et al., 2002). A General Social Survey by Statistics Canada (2013) defined FCGs as people aged 15 and over who responded that in the previous 12 months, they had either a) provided help or care to a person with a long-term health problem or a physical or mental disability or b) provided help or care to a person with ageing-related problems. This could be any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for the patient. The help of FCGs could take the forms of transportation; meal preparations; housework; personal care; medical care (changing dressings or taking medications); organization or planning of care; and management of the care recipient's finances. Taking up these roles is potentially beneficial for patients especially in the context of government cost constraints, when FCGs are expected to take on more of the care once provided by nurses (Ward-Griffin & McKeever, 2000). Consequently, the FCGs and patients' dyad have to make decisions about caregiving – what is required, how to approach caregiving and what support is available. The “informal Care Model” proposed by Broese van Groenou and Boer (2016) highlight the dependence of care decision on many important factors such as the care recipient's needs, attitudes, and beliefs towards caregiving, perceived difficulties, relationship between those involved, the family and social network as well as the community.

A growing segment of FCGs at EOL in Canada consist of family members, friends, and neighbors who simultaneously provide unpaid care to older adults and their own children while also participating in the paid labor market (Duxbury et al., 2009). The time commitment and intensity of care-giving has the potential to escalate in the context of EOL care where informal caregivers are asked to provide care at a time when they are also dealing with their own sense of impending loss. Also, the

demands of caregiving occur as FCGs have to deal with anticipatory grief which can be distracting to them (FCGs) being physically and emotionally present to the dying person. In Canada in 2013, over one quarter (28%) of caregivers, at some point their lives, provided care to someone who was terminally ill, and most often, caregivers providing EOL care were caring for their terminally ill parents (41%) (Statistics Canada, 2013). It is physically exhausting, at the same time be emotionally and financially burdensome (Hudson et al., 2011). It is not surprising that the health and well-being of family caregivers can decline when they provide EOL care at home (Hudson & Payne, 2009). Conversely, family caregiving has considerable rewards such as having positive, empowering, and memorable experiences (Balducci et al., 2008), and allows for FCGs' closure after death and provides meaning in their experiences (Stajduhar, 2003). It is also important to note that in general, studies do not portray all family caregiving as an inherently burdensome experience predisposing caregivers to a variety of negative and distressing psychological and social outcomes. Hudson and Payne, (2009) described this concept as the negative and distressing portrayal as a "pathologizing of the family carer role" (p. 279).

FCGs' contribution to health care systems is crucial considering the amount of physical and emotional care they provide for individuals with life-threatening and terminal illnesses who wish to die at home. Not only are FCGs the 'invisible' providers within the health care system in Canada, but they have emerged as the principle source of support for patients who are dying at home (Stajduhar, 2013). As healthcare systems are confronted with increasing numbers of ageing and terminally ill patients, the question of where people want to be cared for has received considerable attention (Gerber, Hayes & Bryant, 2019). Thus, the feasibility of EOL in-home caregiving is at the center of many EOL decisions and it is particularly dependent upon the efforts of FCGs (Gomes & Higginson, 2006). While providing EOL care at home maybe be the preferred option for many FCGs, it is not without consequences for

FCGs, the patient and the entire family. Challenges for FCGs include being adequately informed to provide care and make health decisions (Stajduhar et al., 2010), developing and maintaining relationships with paid providers (Egan & Horvath, 2006), accessing supports and navigating the health care system, and gaining knowledge regarding pain and symptom management as well as signs of impending death (Ceci, 2006).

Family Caregiver Burden and Immigrants

Kozachik et al. (2001) defined FCG burden in general as a multidimensional bio-psychosocial reaction resulting from an imbalance of care demands relative to caregivers' time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill. FCG burden remains an issue in today's health system partly due to an increase in family involvement in patients' healthcare decisions and the tendencies to de-institutionalize care. FCG are likely to experience caregiving related effects across dimensions that include physical, emotional, and financial difficulty, as well as participation restrictions and work productivity loss (Wolff et al., 2016). The strain of caring for a dying relative has been well documented in the literature to include: stress, anxiety, exhaustion, and depression (Candy et al., 2011). Caregiving burden at home is compounded by challenges associated with EOL such as poor continuity of care, human resource constraints, decreased access, and increased reliance on unpaid FCGs (Armstrong-Stassen & Cameron, 2005; Woodward et al., 2004). EOL in-home caregiving can create ambiguities when the logic and practices of the health care system become superimposed onto the logic and practices of the home.

Caregiver burden arises as immigrant FCGs have to fulfill cultural expectation of EOL part of which was letting a loved one die at home. The promise of a home death was challenged by a) lack of preparedness for caregiving b) difficulty accessing professional support and information c) frustration with the inadequate help received (Topf et al., 2013). This was the case when FCGs took upon in-home

caregiving despite having only a vague idea of what it entailed and with little or no orientation.

Activities such as arranging appointments, meal preparations, and transportation among many others may make FCGs feel unprepared for the amount of work involved. The need for help may not be obvious when FCGs consider EOL in-home caregiving for their loved one particularly when a home death is a promise to the dying person. Stajduhar and Davies (2005) revealed in their study that the promise to provide a home death was of vital importance to the FCGs. If this promise is not met, FCGs may experience profound feelings of guilt, betrayal, disappointment, loss, remorse, and regret. Achieving the promise is further challenged in the case where the FCG (s) is an immigrant(s), potentially making it more difficult for a population already struggling with housing, healthcare access, income issues, and other post-immigration barriers. Another challenge maybe fulfilling cultural desires in a diverse society such as Canada.

Immigrant families like other families depend on each other's support in matters of health, education, and security among others. There are socio-emotional ties and enduring responsibilities that accompany the family (Demo et al., 2000) that are also present among immigrant family members. Foner (1997) stated that the structural constraints and conditions immigrants confront in their new environment shape the kinds of family arrangements, roles, and orientations that emerge among them. For example, constraints with entering the labor market, gaining adequate employment, and pursuing a successful occupational career could hinder immigrant FCGs from fully supporting a loved one dying at home. An immigrant family member supporting a sick relative while adapting and integrating into a new culture can be challenging. The newcomer then is faced with difficult decisions and negotiations when a relative is diagnosed with a terminal disease. Decisions about institutionalization of a terminally ill relative, Goals of Care Designation (GCD), awareness and understanding disease process, when to stop curative measures and initiate palliative care, how to manage informal caregiving at

home, grief, fear, and past experiences become central. Even though the stress associated with these dilemmas can be variable among FCGs, any post-immigration uncertainties could potentially make this burden significantly stressful, especially in EOL in-home caregiving circumstances. Navigating and negotiating care in the unfamiliar terrain becomes significantly stressful for the families dynamic as immigrant FCGs support a loved one at EOL. Immigrant caregiver burden might be highlighted when patients and FCGs have to consider EOL in-home caregiving. Stress occurs when demands outweigh the personal and social resources of an individual (Lazarus & Folkman, 1984), a situation that many immigrant FCGs can be prone to. Studies have found that often, all caregivers gradually lose their social lives as the health status of patients (family members) deteriorates. Consequently, they (FCGs) have to abandon some personal plans and often feel a reduced sense of autonomy and increased feelings of loneliness (Sand & Strang, 2006). Two additional studies showed that service barriers increased the likelihood of depression among older Chinese immigrants and that being an immigrant was the highest cultural predictor for caregiver burden among Chinese individuals (Lai, 2004a; Lai, 2007). These studies support the fact that being an immigrant and at the same time a FCG may lead to stressful outcomes because of the considerable challenges that are inherent in these two attributes.

Suwal (2010) stated that the feelings of reciprocity and the immigrant status of caregivers have a substantial effect on the health and quality of life (QOL) for FCGs. The feeling of reciprocity (responding to a positive action with another positive action) plays a significant role in FCGs providing support even to the detriment to their health. As the care-recipient's ability to self-care decreases, reciprocity becomes increasingly unidirectional (Pearlin et al., 1990), presenting significant negative consequences for the well-being of their caregiver, reported in many studies as caregiver burden (Corà et al., 2012; Robinson et al., 2014). Reciprocity even though rewarding, can be hampered by the attributes of FCG burden. An immigrant FCG's commitment to their sick family members can be

considerable regardless of the impact it has on their health condition. Reviews of concepts related to caregiver research have revealed both negative and positive aspects of family caregiving, including QOL and well-being (Hunt, 2003; Lim & Zebrack, 2004). For any FCG, QOL is a multidimensional construct which concerns the subjective view of the well-being of the caregiver. It includes health and functioning, socioeconomic status, psychological, emotional and spiritual, and family domains (Lim & Zebrack, 2004). Negative concepts are labeled as burdens, hassles, strain, and stress; and positive concepts are considered as caregiver esteem, uplifts of caregiving, satisfaction, finding meaning, and enhancement of the experience (Hunt, 2003).

For the immigrant FCG, the caregiving experience is shaped by sociocultural contexts within which caregiving has personal meaning and social significance (Guo et al., 2019). Culture manifests through components and indicators including, but not limited to language, country of origin, ethnic origin, ethnicity, religious/spiritual beliefs, race, cultural norms, cultural values, and beliefs (Lai, 2007). Cultures have common health beliefs that dictate and explain how people view illness and death. As people migrate, they bring along their cultural beliefs and values which significantly influences the experience of death and dying in their new environment. According to Kirmayer (1989) culture is linked to the way emotions, mental distress, social problems, and physical illness are perceived, experienced, and expressed. For example, some cultures place a substantial value on the community, letting the family make decisions while others encourage individual independence allowing each patient to make their own decision. Immigrant FCGs bring with them culture specific ideas and values related to EOL care and a home death. Some immigrant FCGs may be influenced by the dominant culture of the host country requiring them to blend cultural values for decision making. As such, many immigrant FCGs have to draw on two or more cultures to guide EOL in-home caregiving decisions. This concept supports the view that the immigrant FCG's view of EOL in-home caregiving is enriched

by multiple social relations and cultural influences within and without the borders of their host country. The coming together of these cultural influences for the immigrant FCG and their loved one has bearings on in-home caregiving expectations, how much information about illness and treatment is desired, how death and dying will be managed, bereavement patterns, gender and family roles, and processes for decision making among many others.

There are a limited number of studies that have attempted to understand how the cultural values and norms shape care-giving experiences at EOL among immigrant FCGs. Most studies have used ethnic group differences to understand how FCG burden varies among different cultural groups (Knight & Sayegh, 2010). Dilworth-Anderson et al. (2002) in their literature review argued that immigration should be included as a significant part of cultural diversity when conceptualizing caregiving among immigrants while Berry (1997) concluded that level of acculturation is a particularly pertinent concept to understand the diversity in immigrants' caregiving experience. As such, conceptualizing immigrant FCG burden is challenging due to these two concepts (diversity and levels of acculturation). There is a limited knowledge regarding how cultural values and acculturation shapes immigrants' caregiving experience when supporting a loved one at EOL. Lai (2007) in her study of Chinese-Canadians concluded that despite the filial piety values and beliefs held by these caregivers, they do as non-immigrant caregivers do report challenges and feel the burden. This indicated that the value of filial piety did not always yield positive outcomes for immigrant FCGs. Ng et al. (2016) in their study argued that despite filial piety, many immigrant FCGs have extrinsic motivations for EOL in-home caregiving such as practical demands that can lead to caregiver burnout and burden. For example, even with strong filial piety, immigrant FCGs will experience poorer financial status as a result of in-home caregiving, which is predictive of a higher level of burden (Hudson et al., 2011). Conversely, the same

study (Lai, 2007) reported that if the effects of other confounding factors are controlled for, filial piety is a significant predictor for lower levels of care-giving burden.

Meaning of Home to Immigrant Family Caregivers

The growth in demand for home-based care has prompted a trend towards palliative care delivered in the home (Guerriere et al., 2010; Romanow, 2002). EOL in-home caregiving using other supportive care services has implications not only for the trajectory of EOL care in the community but also on the meaning of a "home" to the patient and FCG. The concept of home is not only constituted by immigrant's habitation experiences of their homeland but also by experiences they have in the new country (Lewin, 2001). Thus, it is important to study the meaning of "home" that immigrants bring with them and the possible transformations these meanings have undergone after immigration. For many, a new home in Canada represents much more than a place to stay. It is an important signal of the start of a new life in a new country for recent immigrants. For new immigrants, finding a suitable place to live in a safe and welcoming neighborhood is an important first step towards successful resettlement and integration. It indicates the essential boundaries of individuals' and families' private lives and shows how they relate to the surrounding society (Lewin, 2001). A new home becomes a safe place for families where cultural sub-identities, values, and beliefs can be expressed freely in a new country. These familial social networks have been associated with better emotional health for immigrants (Fuller-Thomson et al., 2011).

The most predominant view of a home in the nursing literature has been to refer to the place or the setting where people live. A "home" is most frequently used to describe the place where nursing care is provided from a predominately nursing perspective (Gillsjö & Schwartz-Barcott, 2011). The view of home has been enlarged by Hammer (1991) based on the assumption that the feeling of being "at home" is essential to health and well-being which makes it an important issue when planning and

providing health care for immigrants. A home is not just a house; it is a place, relationship, and experience (Gillsjö & Schwartz-Barcott, 2011). Despres (1991) associated a psychological meaning of home with security and refuge, privacy, self-expression, reflection of one's ideas and values, activity and locus for emotional experience. This illustrates how FCGs see "home" beyond a place or a location but a place to connect with loved ones, informed by everyday home activities as well as a physical environment of connection.

Considering that immigrants already experience housing issues, the meaning of a physical location for home care is worth exploring. In 2011, newcomers who had been in Canada for five years or less were almost three times more likely to be in "core housing need" (29.6%) than non-immigrants (11%) even though their (newcomers) housing situation generally improved the longer they stayed in Canada (Canada Mortgage and Housing Corporation [CMHC], 2014). The housing needs of recent immigrants can be characterized by a dependence on rental housing where affordability can be a barrier. According to the CMHC (2014), recent immigrants to Canada are more likely to spend more than 30% of their income on shelter at some point, in part due to their larger average family sizes and tendency to settle in large, expensive cities. Despite the high affordability of housing among new immigrants, they are much more likely to live in crowded households as defined by National Occupancy Standards (NOS) - this definition is based on affordability, adequacy, and suitability (Rea et al., 2008). The dynamic interaction of the circumstances surrounding the migration, housing, and the characteristics of the migrant family, resettlement conditions, and support systems may produce or prevent conditions conducive for the support of a family member at home. With EOL in-home caregiving, the home may be even more significant because of the possible disruption to multiple meanings to the new immigrants (Seto & Angus, 2012). The idea of a home will vary depending on the

FCG, the patient and other circumstances surrounding EOL care making the meaning of home is a dynamic and elusive concept (Collier et al., 2015).

Gillsjo et al (2011) analyzed the meaning of home among older women and found a home to be a relationship and an experience, as well as a physical place to live where people feel comfortable and secure. Further, Moloney (1997) drew a relationship between individuals and their stories of making a home, both in the sense of having a house, and finding a secure and comfortable place in the world. This lends more meaning to a home being more than a house or a physical structure that has in it special relationships between people living in it and their environment. For Dovey (1985), home emerges out of the dwelling activities, the appropriation and the opportunities available in each particular circumstance. It is an insider's experience and it is always unique' (p. 51). The home then becomes a space where personal routines happen, giving the patient and FCG a sense of identity and connected to self, the experience of dying, the health care system and the world. The home provided identity and reinforced their sense of self and identity, autonomy and independence (Saarnio et al., 2016). The FCG and patient will feel rooted and attached to their homes as a secure base from which they reached out to the world. Molony (2010) concluded that self-reconciliation, empowerment, and relationships were recognized as part of the meanings of home – a meaning that is complex, dynamic and varies among FCGs, patients and HCPs. In light of this study, the concept of a home appears to be a space created by patients and FCGs allowing for support of a dying loved one physically and psychologically. It is a space, an experience and an environment that is comfortable and safe both for the body and the mind. In the context of palliative care, a common focus has been on the home as place, i.e., the location where many people wish to spend the last months of their lives and die (Tryselius, Benzein & Persson, 2018). Consequently, the home becomes a place and an experience with relevance to the immigrant FCG, patient and the multidisciplinary team.

Immigrant FCGs and EOL in-Home Caregiving

In their study, Gomes and Higginson (2006) identified factors affecting a place of death a) factors related to illness b) individual factors and c) environmental factors. For many Canadians including immigrants, a combination of these factors make the home a preferred option for FCGs and patients with a progressive illness. Tryselius et al., (2018) in their research showed that the private home becomes a central position in processes of palliative care and dying. Achieving a home death for a dying loved one is seen as the epitomes of the ‘good death’ while an institutional death conjures images of a technical, impersonal and even inhumane demise (Seymour, 1999). EOL in-home caregiving takes on a new dimension for immigrant FCGs for whom the “home” already has complex meanings when supporting a terminally ill patient at EOL. The new meaning of a home may support dialogue among those involved in organizing care, and at the same time promote a better EOL in-home caregiving experience of patients and immigrant FCGs. Thus, EOL in-home caregiving then becomes a major event for immigrant caregivers with significant effects on health, employment, and finances. Delivering EOL care at home may be complicated more by the heterogeneous nature of immigrants, the disease conditions, and the variability in the home environment. This unpredictability is compounded by the barriers of adequate housing and health system literacy common among immigrants. The ambiguities in housing, logistics, cultures, beliefs, and immigration experience add to the complexity in EOL in-home caregiving. For example, immigrant FCGs must learn to negotiate through an altered space that becomes a site of EOL in-home caregiving with unfamiliar equipment and a succession of different HCPs (Seto & augus, 2012).

Another major challenge for immigrant FCGs is effective communication during EOL in-home caregiving. Increase in immigration means HCPs are challenged to effectively communicate treatment options, provide patient education, deliver follow-up care, and aid in decision making for a culturally

diverse population. HCPs may fail to address the particular perspectives unique to immigrants of in-home caregiving and other palliative care services at EOL. HCPs may have different goals and interests than the care recipient and FCGs, which may necessitate a process of negotiation (Oresland et al, 2011). While supporting a loved one at home is the prerogative of the patient and family, the FCG experience of caregiving could be affected by factors such as a lack of knowledge about what the responsibility for caregiving entails, an unrealistic sense of expectations, a sense that there was no choice, and pressure from the health system. As such, an undertaking to appreciate how immigrants to Canada experience EOL in-home caregiving becomes important for the health care system to better serve a significant proportion of the population.

Summary

The home is the preferred location of death for most Canadians of whom immigrants are a significant subset. While choosing a home death could be a rewarding and meaningful experience for the immigrant FCGs, it could also be accompanied by feeling of being overwhelmed with caregiving responsibilities. This choice is guided partly by cultural beliefs and values about EOL in-home caregiving expectations, beliefs and values which influence almost every aspect of this dying experience at home. Decisions on how; when, and where to provide EOL in-home caregiving is rooted in the immigrant FCGs' and patients' expectations of death and dying. For a culturally appropriate in-home caregiving, immigrant FCGs have to consider all of their options for a terminally ill loved one. Like most Canadian-born FCGs, the preferred location for death by immigrant FCG is home. The vast amount of literature reviewed makes it evident that the immigrant experience of EOL in-home caregiving is a complex concept requiring the consideration of multiple variables to understand each FCG's unique circumstances. A consensus on the general immigrant experience of EOL in-home caregiving is challenging due to the heterogeneity of the immigrant population.

The next chapter will discuss the methodology of constructivist grounded theory and the steps taken to conduct the research for this study.

Chapter Three: Research Design and Methods

In this chapter, I will outline the different types of Grounded Theory (GT) and provide a historical overview of the development of GT. Particular attention will be paid to Constructivist Grounded Theory (CGT) as the chosen methodology for this study, as I focus on the aptness of CGT in answering this study's research question. The discussion of CGT to explore how immigrant FCGs experience in-home caregiving in the Calgary Zone, Alberta will be the focus for this chapter. I will also discuss some of the philosophical underpinnings of CGT. The goal of my research was to generate a substantive theory that is interpretive of immigrant FCGs' EOL in-home caregiving experiences in the Calgary Zone. In this chapter, I will also provide an overview of how the study was conducted using the methods of CGT.

Historical Overview of GT

The origin of GT has unequivocally been attributed to two American Sociologists, Barney G. Glaser and Anselm L. Strauss. GT arose because of Glaser and Strauss's disenchantment while undertaking a study on the awareness on death and dying which led to their seminal work the "Awareness of Dying" (1965). This disenchantment was against the backdrop of the popularity of the excessive belief in the power of scientific knowledge, technique, and quantitative research as reliable sources of truth. In social sciences, qualitative research did not fit this quantitative methodological framework with its logic of quantifiable measures of reliability and validity as well as research designs that made replication possible (Charmaz & Flick, 2014). As such, the methodological criteria for qualitative research were not authenticated with the standards set by quantitative research. This led to general and abstract theorizing without verifiable proof and methods of authentication. For Glaser and Strauss, (1967), they proposed that a theory generated from social research should be "more successful

than theories logically deduced from a priori assumptions” (p. 6). Such theories would have to be context-specific and be embedded in the data from which they had emerged rather than relying on analytical constructs. They argued that during the process of generating a theory, not only do the concepts and hypothesis directly emerge from the data, but they have also been systematically refined by it (Kenny & Fourie, 2014). Glaser and Strauss’ GT are inductive and not deductive, with no preconceived hypotheses to prove or disprove, in order to uncover the concerns of participants. Consequently, Glaser and Strauss called their innovative methodology GT in order to encapsulate its overarching objective to ground theory in research data. Since its inception in the 1960s, GT has unfolded into multiple versions over time. The three most prominent GT paradigms include: Classic GT (Glaser & Strauss, 1967), Straussian GT (Strauss & Corbin, 1990), and Constructivist GT (CGT) (Charmaz, 2006). The last two paradigms were a result of continuous evolution of GT and also due to the intellectual divergence in the 1970s and 1980s between Glaser and Strauss. Straussian GT focused less on the emergence of data and more on validating data while CGT employs co-constructing meaning from the data from the perspectives of the researcher and participant (Bryant & Charmaz, 2007; Charmaz, 2014). Glaser’s education of rigorous quantitative research led to the use of a logical and systematic approach to GT through coding and guidelines, with an emphasis on emergent discoveries (Charmaz, 2014). Conversely, Strauss embraced a pragmatic perspective through his doctoral studies, which guided his view of people as active agents in their environments instead of passive recipients of larger social influences (Charmaz, 2014). Strauss also adopted the theoretical perspective of symbolic interactionism, which focuses on a reciprocal relationship between meaning and human actions; people construct meaning of self, society, and reality through interaction (Annells, 1996; Charmaz, 2014). CGT as the most recent development of GT was aimed at substantive theory

development that is interpretative in nature and theorizes the connection between concepts that are interrelated.

Constructivist Grounded Theory

Epistemologically, constructivism emphasizes the subjective interrelationship between the researcher and participant, and the co-construction of meaning (Hayes & Oppenheim, 1997; Pidgeon & Henwood, 1997). Strauss and Corbin (1994) did not believe in the existence of a pre-existing reality out there. As such, reality is one that is socially constructed and relativistic contrary to the quantitative positivistic view where society shapes the individual by using scientific methods. According to Ponterotto (2005) *positivism* is a quantitative paradigm that relies on hypothetico-deductive method to verify a priori hypotheses in order to have a causal relationship between explanatory factors (independent variables) and outcomes (dependent variables). The work of Glaser and Strauss opened the possibilities for a shift to post-positivism and constructivism paradigms which were adopted by their student Charmaz. Positivists accept an objective, understandable reality while post-positivists acknowledge an objective reality that is only imperfectly apprehendable (Lincoln & Guba, 2000). Charmaz (2000) emerged as the leading proponent of CGT. Charmaz (2000) in contrast to Strauss and Corbin (1988) argued that there is no discernible reality; to ask analytic and methodological questions, Strauss and Corbin had to assume an external reality. As such, CGT qualitative research is ontologically relativistic and epistemologically subjectivist based on an evolving interaction between researcher and participant as part of the research process. Discussing the position of Charmaz in CGT, Annells (1997c) suggested that it applies the strategies of traditional GT within a constructivist paradigm, thus rejecting the notions of emergence and objectivity. Charmaz contends that “data do not provide a window on reality, rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (Charmaz, 2000, p. 524). As such, meaning is constructed from the

data with potential for multiple meanings of a particular concept to different participants. Researchers explore more than what participants state to uncover the values, beliefs, and ideologies that define meaning for them (participants). Charmaz (1995b) positioned researchers as co-producers, exhorting them to “add a description of the situation, the interaction, the person’s affect, and [their] perception of how the interview went” (p. 33). As such, it is a prerogative of the researcher to immerse themselves into the realities of their participants to produce data that is reflective of their participants. Charmaz (2000) argued that constructivist grounded theorists are compelled to be analytical in their writing but that their style of writing needs to be evocative of the experiences of the participants. The participants’ voices have to be active without being overshadowed by the researcher’s voice or interpretations. It is the researcher’s ethical obligation to “describe the experiences of others in the most faithful way possible” (Munhall, 2001, p. 540), keeping the researcher in a position of a “distant expert” (Charmaz, 2000) and co-participant. The paradigm of CGT strives to maintain the participants’ presence throughout the study. GT illuminates common issues for people in a way that allows them to identify with theory and use it in their own lives.

Philosophical Underpinnings of CGT

The goal of this study was to establish a theory together with participants, through methodical gathering and analysis of data for a better understanding of immigrant FCGs experience of caring for a loved one who is dying at home. Considering common epistemological and ontological underpinnings to CGT methodology and being conscious of my own knowledge and experience with FCG burden, I will uncover why Pragmatism and Symbolic Interactionism are relevant and underpin the CGT methodology.

Pragmatism

Pragmatism refers to knowledge as a source of social utility (Udod & Racine, 2017). This definition supports the practicality of any qualitative research findings, how these findings inform practice and policies. GT methodological findings are practical because they arise from reality as perceived and interpreted by the study's participants (Udod & Racine, 2017). Epistemologically, the meaning of an idea is the practical consequences of that idea and 'truth' is only attainable through its practice (American Pragmatism, 2011). A pragmatic view of research emphasizes the knowledge translation (KT) of its findings – what works, how it works, and why it works and vice versa. A pragmatic approach to KT allows for the consideration of multiple theories, ideas, and perspectives with a focus on the usefulness of this knowledge to create new knowledge (Doane & Varcoe, 2005). This view suggests that research data and outcomes ought to be aimed at problem-solving, not just for philosophical understanding, and not just for researchers but for practitioners also.

In nursing research, this pragmatic approach permits stakeholders to acknowledge and apply data in ways that are inherently practical and helpful in everyday nursing practice. According to Nowell (2015), one of the most significant implications of bringing together a KT and a pragmatic approach is the inclusion of practicing nurses, policy makers, and the public in the knowledge creation process. This guarantees that study findings are not just in abstractions and useless theories but have practical accountability to nurses and other HCPs in the field. Consequently, any nursing knowledge created can then be effectively evaluated through the pragmatic approach by examining what works in practice (Carr, 2009).

Symbolic Interactionism

Symbolic interactionism is a theory based on the research pioneered by American Philosopher George Mead and picked up by his student Blumer who coined the term Symbolic Interactionism.

Symbolic interactionism is an empirical social science perspective on the study of human group life and human conduct (Blumer, 1969). This theory supports the idea that the “meaning” of symbols is not always obvious but can be made so by negotiations through social interactions with others and self via communication. According to Benzies and Allen (2001) “symbolic interaction provides a theoretical perspective for studying how individuals interpret objects and other people in their lives and how this process of interpretation leads to behavior in specific situations” (p. 544). Interactions become symbolic when individuals interpret and define objects and their own or another’s actions and act on the basis of assigned meanings (Chamberlain-Salaun et al., 2013). Symbolic interaction is an interpretive process based on the assumption that an individual cannot be separated from the context of their environment. Social interactions offer epistemological data as individuals communicate with self and others.

In symbolic interactions, language is an important tool as it predicts how an individual interacts with the larger society so that they understand and are understood. Meaning derived from these interactions is ever-changing as individual perspectives change. According to Benzies and Allen (2001), people have the cognitive capacity to be abstract and reflective in their thinking enabling the development of the symbolic use of language and gestures. Symbolic language creates and communicates meanings that have the potential for common and understandable responses in interaction with others. In other words, language, thoughts and meaning are socially constructed realities which are contextually based.

Implications of Constructivist Grounded Theory to the Research Question

CGT is commonly used in nursing research to understand experiences and describe social processes to enhance patient care (Higginbottom & Lauridsen, 2014). The goal of my CGT study is to generate a theory that can be used by HCPs and other stakeholders to understand the immigrant FCGs’

experience with EOL in-home caregiving. According to Bryant (2002), a constructivist not only theorizes the interpretive work that research participants do, but also acknowledges that the resulting theory is an interpretation. As such, CGT theories developed on immigrant FCGs' experience with in-home caregiving will be inherently interpretive for immigrant FCGs and subject to variations in immigration experiences, home settings, and FCGs-patient preferences among others. Even though a CGT theory might have overarching presence on immigrant FCGs' experience of EOL in-home caregiving, different FCGs can arrive at multiple meanings of this experience depending on place and time. The subjectivity of meaning implies that there is not simply one external reality or truth but rather multiple, constructed realities (Charmaz, 2014). Immigrant FCG characteristics that can influence meaning of in-home caregiving in Calgary Zone, Alberta include but not limited to: years in Canada, experience, prior knowledge, negotiation skills, gender, ethnicity, religion, and cultural background. The use of Charmaz's CGT to answer my research question sought to capture all these complexities, making meaning from data and rendering immigrant FCGs' experiences into readable theoretical interpretations. Symbolic Interactionism and Pragmatism tenets of action and interaction enable the student researcher to interact with immigrant FCGs in ways that concurrently generate, collect, and analyze data, and then support the theoretical sampling of the rest of the participants. According to Shalin (1986), there is consensus among authors about the profound impact of pragmatist philosophy on social interactionism. Many authors consider pragmatism as a precursor of symbolic interactionism (Shalin, 1986). These philosophical underpinnings of Charmaz's CGT dismiss the notion of a researcher being a neutral observer but rather take the researcher's perspectives and interactions into account as an inherent part of the research reality (Charmaz, 2014). This involves the student researcher forming a partnership with the immigrant FCGs to guide the researcher in exploring the multiple realities of in-home caregiving among this population in the Calgary Zone, Alberta. This relationship

has elements of mutuality and reciprocity, consistent with a constructivist approach. These tenets form part of the student researcher's investigative strategy for this study.

In relation to Social Interactionism, this study supported the immigrant FCG use of language (verbal or non-verbal) as a part of the interaction process to generate meanings of FCG's caregiving experiences that is flexible and comprehensive. Consequently, shared realities and new understandings of this experience emerged to support a co-constructed theory that is both interpretative and context based. Without necessarily acknowledging the concept of symbolic interactionism, participants in this study evoked ideas related to interconnectedness and social support which were instrumental in their adaptation to the caregiving role. It is through creating a shared meaning that the researcher and immigrant FCGs can name arbitrary signs like immigrant FCG burden, cultural expectation, dignity, reciprocity, and attach meaning to it. This way HCPs and immigrant FCGs, patients and immigrant FCGs, family members and immigrant FCGs can symbolically interact in a manner that highlights meaning, language, and thinking (three central elements of symbolic interactions) for a better understanding of immigrant FCG experiences. In relation to the pragmatic philosophical underpinnings of this study, Knowledge Translation (KT) intuitively and automatically assumed high levels of significance due to its emphasis on nursing practice. KT frameworks offer a pragmatic approach to KT allowing for the consideration of multiple theories, ideas, and perspectives with a focus on the usefulness of this knowledge to create new knowledge (Doane & Varcoe 2005). In adopting a pragmatic approach to my research question, knowledge generated was understood as being constructed based on the reality and feasibility for the FCGs. The CGT theory that ensues from this study captured these complex realities of immigrant FCG experiences of in-home and how it could be used for interpretative purposes for future understanding of immigrant FCG experiences in Alberta.

Sampling and Recruitment

Purposive sampling was used to initially recruit participants who had knowledge and experiences of the topic of this study. A purposive sample is a type of non-probability sample with the main objective to produce a sample that can be logically assumed to be representative of the population (Lavrakas, 2008). Then, theoretical sampling was used to bring “explicit systematic checks and refinements into analysis” (Charmaz, 2014, p. 381). Theoretical sampling is similar to purposive sampling in that selecting participants is based on specific characteristics. The difference between the two lies in the stage at which participants are selected. According to Streubert and Carpenter (2011) theoretical sampling is a type of purposive sampling that can be used to obtain individuals who have specific experiences that inform the research project. Theoretical sampling was significant to my research for two main reasons: a) it sought and collected pertinent data to elaborate and refine categories for an emerging theory (Charmaz, 2006), and b) it was responsive to the data collected and allowed for a flexible process (Corbin & Strauss, 2008).

Participants were recruited from the Alberta Health Services (AHS) PHC program and the Palliative Care Consult Service (PCCS). The researcher approached the Area Manager of AHS PHC and PCSSs Calgary Zone for permission to access HCPs such as Care Manager of PHC, Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and Social Workers who can identify and recruit potential participants. It is important to note that the term EOL in-home caregiving was inclusive of all supporting a loved one at home regardless of which department (PHC or PCSS) assessed them. The writer attended multiple team rounds to discuss the study with the PHC team. These HCPs in collaboration with patients identified immigrant FCGs. Due to restrictions imposed by the COVID-19 pandemic, the student research worked primarily with the PCCS for participant recruitment. An invitation for research participation was given during consultations, PHC visits, meetings and events of

the AHS PHC. Additional information about the study was provided upon request to potential participants by the researcher with an opportunity to have their questions answered.

Inclusion Criteria

Inclusion criteria for selection of participants included:

- (a) Primary FCG providing EOL in-home caregiving who is an immigrant
- (b) 18 years and above
- (c) Expression of interest in the topic
- (d) English speaking
- (e) Consent to participate (Appendix A).

The student researcher contacted potential participants directly in person or via email after they showed interested in participating in the research study via their palliative care HCP. The sampling in this study stopped when I achieved data saturation – a phase of emerging robust theoretical categories in which no new properties are found (Charmaz, 2014).

Data Collection

Charmaz (2014) emphasized the importance of using data collection methods that will help the researcher to answer the research question with ingenuity and incisiveness. For a concise exploration of my research question, participant interviews were appropriate and efficient ways of data collection. To ensure safe environments, all the interviews were conducted via zoom by the researcher at a mutually agreed time at the participant's convenience. Interviews lasted for 45 to 60 minutes. During interviews, semi-structured questions were used because of its potential to begin the conversations and elicit data (Charmaz, 2006), particularly using the interview guide (Appendix B). Starter questions such as: "how," "what," "when," or "tell me about" were asked to generate details securing rich data. Related questions were directed at the participants for clarifications of meanings, exploration of assumptions,

and content saturation. Participants were encouraged to describe and reflect on their experiences of in-home caregiving.

Interviewing process: Interviews were conducted to gently guide conversations that explored immigrant FCGs' perspectives on in-home caregiving in Alberta (Charmaz, 2014). Through intensive interviews, I traced ideas of immigrant FCG burden as they emerged, analyzing this data, and returning to the field to gather more focused information until saturation was reached. Through probing questions, the student researcher tried to uncover the participants past experiences with in-home caregiving that informed their knowledge of the EOL in Alberta. Memos were written after each interview to capture a systematic and detailed account and interpretation of the ideas of the session. As there were no other research team members to take field notes, the student researcher used his memos to capture this piece of data.

Another strategy used to assist in the assimilation of information, was to listen to the audio-recordings as close to the time of the interview as possible. This allowed the capturing of fresh perspectives/insights into the data. One to one interviews were audio-recorded after informed consent (Appendix A) was obtained from all participants. All of the audiotaped data from one-to-one interviews were transcribed verbatim into text by the student researcher.

Data Analysis

In CGT data analysis commenced immediately after the first interview. Comparative analysis was applied followed by a process of initial coding, focused coding, in vivo codes, memo writing, theoretical coding and creation of an overarching theory (Charmaz, 2014). The researcher used developing threads and perspectives from the data of the first interview to direct and enhance the questions in subsequent interviews. Constant comparison was accomplished by reviewing the data numerous times while observing for new codes, categories, patterns or ideas.

Initial Coding: Initial codes helped separate data into categories and to identify processes (Charmaz, 2014). Initial coding was used early on as an open exploration to begin to determine theoretical possibilities in the data. In reading through the transcripts for initial codes, the researcher identified prompts that suggested and supported the development of patterns. Emerging codes were put in red ink on the sides of the transcripts as analysis went on. Coding prevents the researcher from attributing prior prejudices of the topic to the participant's voices and consequently the data (Charmaz, 2014). In this study, I analyzed the first transcript before interviewing the second participant in accordance with the "constant comparison process" (Charmaz, 2014).

Invivo codes: During the process of documenting memos, the student researcher noted and recorded the words/phrases that were repeated throughout the interviews. Charmaz (2014, p. 343), described these as “codes that I adopted directly from the data, such as telling statements they discovered in interviews.” Invivo codes were sorted according to each participant and placed into columns on large poster paper. This visual re-presentation of the data assisted the researcher to notice common patterns of the immigrant FCG experience of in-home caregiving in Alberta.

Focused Coding: Focused coding means using the most significant and frequent earlier codes, sifting through and analyzing large amounts of data (Charmaz, 2014, p. 283). As new understanding of immigrant FCG experience of EOL in-home caregiving emerged through data analysis, the researcher used the comparative process to compare initial codes, identifying commonalities, and grouping them into major categories. The student researcher and supervisor engaged in focused coding to advance the theoretical direction of their work by concentrating on the most significant or frequent codes to “synthesize, analyze, and conceptualize larger data segments” (Charmaz, 2014, p. 138). It was important for the researcher to be reflexive throughout the coding process, and examine how personal experiences, assumptions, and interpretations may be influencing the research (Charmaz, 2014).

Theoretical Coding: The goal of this coding is to identify a core process that includes most, if not all, of the categories and integrate the information into a narrative statement with an explanatory relevance (Strauss & Corbin, 1998). The researcher accomplished the final task of analysis by moving towards the theoretical selection of a core process, examining the categories for evidence of connections, and then relating all other categories to the core process. Whilst focused coding facilitates the organization of the codes and concepts into higher level categories established from initial coding of my transcripts, theoretical coding enabled the saturation of the major categories identified during focused coding. According to Charmaz (2014) theoretical coding integrates and solidifies the analysis in a theoretical structure and emergent theoretical codes keeps the analysis creative and fresh.

Memo Writing: Memos served as analytic tools (Charmaz, 2006, p.72); and helped me reflect regularly on the data collection procedure and the actual data collected. Memos provided insight into the participant's experience of EOL in-home caregiving, and were helpful in deliberating reasons for some participants in holding a particular point of view of EOL in Alberta. Written memos are enabling tools, allowing this researcher to reflect on the whole research process, from data collection, analysis, and write-up. Memo writing at the early stages of this CGT study allowed the emerging concepts of benefits and challenges in-home caregiving to develop into major categories and subsequently the theoretical codes. The quest for an overarching conceptual theme(s) is contingent on the researcher's ability to compare and contrast codes and categories for any significant relationships among them. As such, the researcher's thoughts serve as a guide for a thorough examination of the interviewees' responses, going beyond their statements in search for meanings and relationships

Rigor/Trustworthiness

The existential concerns about rigor in qualitative studies necessitate researchers to take responsibility to ensure rigor in their studies (Cypress, 2017). To attain rigor in my research is to

represent the experiences of immigrant FCGs in in-home caregiving accurately. To be consistent with CGT methodology, I explored four central guidelines put forth by Charmaz (2014) to ensure rigor: credibility, originality, resonance, and usefulness to judge the value of my study's contribution.

Credibility: Credibility is the "confidence in the truth of the data and interpretations of them" (Loiselle & Profetto-McGrath, 2011, p. 276). Prolonged engagement with my data (Streubert, 2011) and intimate familiarity with my related literature helped me to establish credibility (Charmaz, 2014). I achieved this familiarity by conducting all the interviews, transcribing all of the interviews, and analyzing data myself as outlined by Charmaz (2014) and have my supervisor review the first few transcripts with my initial codes to confirm that my codes are emerging from the data. Additionally, member checking was critical in improving the credibility and validity of my study by presenting the findings to FCGs to see if they recognize my interpretations. Member checking also ascertained that the course of the interviews is not researcher directed but rather the stimulation of FCGs to express their experiences about EOL in-home caregiving.

Originality: The literature on FCG burden has grown immensely in recent years with substantial research for better understanding FCG burden as a concept. However, there is less information on the process of how immigrant FCGs experienced EOL in-home caregiving while supporting a loved one at home in Alberta. However, a theoretical model offered new understandings and interpretations of immigrant FCGs' experience of EOL in-home caregiving. The emergent theory provided a platform for multiple meanings of immigrant FCG burden, expanded the scope of knowledge through new insights, and added to the existing body of literature.

Resonance: Charmaz (2014) suggested asking whether the study fully represented the studied experience and ensured that all underlying meanings have been explored. Through the interviews, I gained rich, detailed information from participants about their experiences of EOL in-home caregiving

in Alberta. My objective was to have categories that resonate with immigrant FCGs – a result of insightful thoughts of the meaning of EOL in-home caregiving from personal experience. My study had substantial resonance because it was consistent with other FCGs' experiences documented in the existing literature, such as the caregiving literature in this study (Charmaz, 2006). The theoretical sampling, member checking, and reviews from my supervisory committee helped me to achieve resonance. I compared my findings with similar studies in the research literature to assess the study's resonance.

Usefulness: My analysis in this study offered interpretations that were useful for HCPs in palliative care practice settings and for immigrant FCGs. Understanding how immigrant FCGs negotiate in-home caregiving and palliative care services as a process brought clarity to the caregiver role for the study population, distinguishing it from FCG burden experienced by Canadian born citizens. This emergent theory is important for contextual interpretations and predictions of FCGs' experiences of EOL that takes into considerations the immigration status of caregivers. Finally, my results were helpful for stakeholders of the palliative care home care departments for the development of policies and procedures for caregiver burden assessment for immigrants in Alberta.

Ethical Considerations

Participants were provided with the consent form before commencing with interviews, and I explained and asked to clarify any issues regarding confidentiality and anonymity. Every attempt was made to exclude identifiers to the patient and their primary FCG; I used pseudonyms during data collection and analysis. Participants were made aware that they could withdraw their consent at any time with no negative consequences and that all data they had contributed would be destroyed before data analysis. I obtained approval for this study from the Conjoint Health Research Ethics Board (CHREB) as well as administrative approval from AHS. All data were managed securely, as previously

discussed, to protect participants' confidentiality and anonymity. A password secured computer was used and stored in a locked cabinet in my house. No interviews caused any distress to the participants. However, I ensured the participants knew that they could decline to answer any questions. I also softened some questions, as Charmaz (2014) suggested, by starting with insights from earlier interviews or even my own experiences.

Summary

The main focus of my research is to understand the core process of how immigrant FCGs experience in-home caregiving of a family member with a terminal disease. A CGT methodology captures the complexities of this phenomenon, unveiling the realities of the core process without ignoring the immigrant FCGs' unique experiences. Consequently, a co-constructed theory can be developed that elicits multiple meanings of this experience in a manner that is interpretive and adaptive to different contexts.

Chapter 4: Data Analysis and Findings

This chapter describes the experiences and the resulting substantive theory of immigrant Family Caregivers (FCGs) taking care of a loved one at home. Previous studies have suggested an increased burden for informal FCGs supporting a loved one at home (Seow & Bainbridge, 2018; Tryselius, Benzein & Persson, 2018). The literature implies that caregiver burden for End-of-Life (EOL) at home is complex and multifaceted. This study's primary focus is to understand the experience of being an immigrant, a FCG, and supporting a loved one at home. I used a Charmazian Constructivist Grounded Theory (CGT) methodology to explore the primary research question: *What are the EOL in-home caregiving experiences of immigrant family caregivers?* With CGT being interpretive, the researcher and participants co-constructed the meaning of the data and brought forth a theory that captures the notion of shared reality of being an immigrant family caregiver for a loved one at the end of life.

This chapter describes the experiences of EOL in-home caregiving of the study participants – Melissa, Jasmin, Glory, Nasa, Camille, Stella and Amanda. Participants' data are quoted verbatim with a demonstration of how they are instrumental in the development of the theoretical model. The theoretical model (*Immigrant FCG experience of caring for a loved one at home: A Relational Process of Maintaining Dignity in Dying*) that emerged from the iterative process of data collection and analysis, identified from in-depth interviews with seven family caregivers supported by verbatim accounts of their experiences. This resulting substantive theory captured the unfolding experiences of immigrant FCGs with in-home caregiving in the Calgary Zone.

Participants

Demographic data (Appendix C) were collected to describe the characteristics and unique caregiving status of the sample as described below. A total of seven participants, all females, were

interviewed via the University of Calgary licensed Zoom platform. The mean age of the sample was 57.7 years (32 years – 69 years) and the average number of years since immigration was 15.9 years (4 years – 23 years) – a summary of participants’ characteristics were shown in Appendix D. Participants in their interviews described their in-home caregiving experiences with self, their loved ones, the healthcare system, and other family members; with all participants having received some form of formal of assistance from the palliative care services. Data collection took place over 16 months from June 2019 to February 2021 as participant recruitment was delayed because of COVID-19 public health measures and recruitment challenges with the PHC and PCCS of Alberta Health Services.

Participant 1 (Melissa)

Melissa is an Iranian-Canadian immigrant, the primary caregiver and daughter-in-law to a female care recipient in her nineties. The entire family immigrated from Iran in 1983. This participant began caring for her mother-in-law approximately 23 years ago after her father-in-law passed away. She had quit her managerial position in a travel company to become a full-time caregiver about eight years ago. She has two adult children who live in the city and occasionally provided caregiver relief when needed. Her mother-in-law was diagnosed with terminal lung cancer three years ago and has been at home while she received some professional palliative care support ever since. Melissa described many challenges of caring for a person with cancer, citing physical and mental changes as prominent.

Participant 2 (Jasmin)

Jasmin is a Canadian of Indian origin. She was a primary caregiver to her grandmother (84 years of age). Jasmin began taking on a more significant caregiving role about 10 ten years ago when her grandfather passed away. Her grandmother was officially diagnosed with Alzheimer's disease in 2012, and in 2018, she developed breast cancer. Jasmin immigrated as a child with her family in 1996. Now

in her 30s, she was in school while taking care of her grandmother during the interview. She lives with her parents, brother and grandmother in the same house. The rest of the family members also help to provide support to her grandmother. Jasmin described her caregiving role as “intense” particularly when dealing with her grandmother's aggressive behaviors. She also reported being grateful for the informal support from other family members and formal PHC service she received while caring for her grandmother.

Participant 3 (Glory)

Glory is a Canadian of Indian origin. She took care of her mother who passed away a couple of months prior to the interview. Glory currently in her 30s and immigrated to Canada with her family in 2005. She was a nurse in India, so she had an informed understanding of medical knowledge related to her mother's condition. Her mother had a tracheotomy which impacted her ability to communicate verbally. As the primary caregiver, she lives with her family and shared caregiving responsibilities with them. She was grateful that her mother could experience her wedding before passing – this was a meaningful experience for her. Glory put her career and education on hold to take care of her mother.

Participant 4 (Nasa)

Nasa is a middle-aged woman who is caring for her mother-in-law in her nineties. This care recipient and caregiver immigrated to Canada from India in 2001. Nasa speaks Punjabi and English at home. She quit her job to take care of her mother-in-law but still had to hire private caregivers to assist with the caregiving. She revealed that food preferences and language barriers were two fundamental reasons that contributed to the decision to have her mother-in-law stay home. Nasa believes that in-home caregiving and PHC services were beneficial because it meant she and her family could see her mother-in-law at any time.

Participant 5 (Camille)

Camille is a 61-year-old female taking care of her husband. Camille immigrated to Canada from the Philippines 30 years ago and is married to an African immigrant for 25 years. She has been the primary caregiver for her husband for 15 years. Her husband had kidney failure with frontal lobe dementia. She described caregiving challenges were associated with increased care needs and behavioral changes of her husband. Camille continues to work full-time and manage her husband's complex needs with the assistance of PHC services at the time of the interview.

Participant 6 (Stella)

Stella is a primary family caregiver in her fifties who cared for her father in his eighties. Her father lived in the same household until his passing last year. Stella was born in Ukraine and immigrated to Canada in 2006 with her children after a divorce. Her father immigrated to Canada about a decade later before he became ill in 2017. She began caring for her father as soon as he moved to Canada – he was sick before his immigration. Stella reported that keeping her father at home and avoiding placement in an institution was a part of her upheld culture. In-home caregiving was made possible by complementary PHC services. Keeping her father at home meant she had a father figure for her children, who benefited by learning about their Ukrainian heritage.

Participant 7 (Amanda)

Amanda is a Filipina-Canadian caregiver in her fifties. She is the care recipient's daughter, who is in his nineties and lives with the primary FCG's brother. She moved to Canada in 1993 after living in Greece for a while. According to Amanda, her father has lung cancer and has become weaker since staying home due to the COVID-19 pandemic. Both the participant and her family are devout Catholics, and their wish is to have her father spend his last days in the Philippines before he passes.

At the time of the interview, Amanda and her family were actively coordinating with PCCS to manage complex needs of her father and enhance his safe travel for him back to the Philippines.

These descriptions provide a glimpse into the lives of the immigrant FCGs, touching on the uniqueness and complexity of their caregiving situations. I learned from my participants how they made sense of their caregiving experiences and through data analysis, the constructed grounded theory of immigrant family caregiving at home was revealed. The following section will briefly show the structure and process of grounded theory coding followed by a description of the emergent theory and findings.

Data Analysis: Building Substantive Theory

In constructivist ground theory (CGT), coding links collecting data with the development of an emerging theory (Charmaz, 2014). The coding process moved the data from initial codes to focused codes and finally to theoretical codes as shown in Appendix E. The coding process started with the initial coding phase where I read the entire data document line by line and I labeled bits of data according to what they indicated, naming significant words, lines, or data segments to begin conceptualizing my ideas.

Focused Codes

The second stage of coding, is focused coding where I selected the most important or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data (Charmaz, 2006). In working through these codes, I assessed initial codes by comparing them with data and distinguishing them from each other (constant comparative analysis) to have theoretical centrality of certain ideas as described by Charmaz (2014). All focused codes were supported by the participants' responses to interview questions and were "grounded" in data. These codes emerged from the interview data,

offering an enhanced understanding of the caregiving experience at home. I used probing questions such as “what is this data suggesting”, “from whose point of view”, to gain insight into the participant experiences to conceptualize the focused codes. Consequently, four focused codes that were closely connected and affected each other developed from the data. The four interrelated focused codes that emerged from the initial codes were: (1) Cultural Values, (2) Family Caregiver Reciprocity, (3) Preparedness, and (4) Resilience (Appendix E)

Firstly, *Cultural values* was a focused code that was both evident and subtle from the interview data. In this study, cultural and family values were nuanced but remained influential in EOL caregiving and the reception of formal palliative care services. *Cultural values* in this study referred to the outside influences that shaped participants’ beliefs on the need and importance of a home death for a loved one. This was frequently cited by participants as any form of a societal expectation to keep a loved one at home for EOL care. An example of a cultural value expressed by Camille and Amanda both Filipinas was the importance placed on honouring and respecting elders in the family. Another example of a cultural value was articulated by Glory who said “[in] the Indian culture we feel like we stay closer to our family members, we feel like if you are taking care of your loved one [you have to] do it all by yourself”. Cultural values were distinguishable from *family values* – a strong identification with the family and strong feelings of loyalty among family members so that a loved one will remain at home for EOL. Camille supported the idea that EOL in-home caregiving was a family value by saying

It [EOL in-home caregiving] is also because that is the way we were raised. We love our family that is why back home, we do not send our family [to institutions], we take care of them whether old, young we are taking care of each other.

Participants frequently used these two concepts (cultural values and family values) interchangeably making it challenging to differentiate the two. This was the case of Glory who addressed the reasons to keep her mother at home for EOL when she said

[Our] decision [to keep her mother home] is culture based and driven based on how we are raised so and my dad and my mom's wishes that we take care of her at home, rather than taking her to any facility.

Secondly, *family caregiver reciprocity* implied mutual sharing of emotion felt or shown by both immigrant FCGs and their loved ones. Other codes in the data that spoke to reciprocity were mutuality, cooperation, presence, and exchange which were expressed in the form of a) rallying informal support and b) coordinating care. These words were used or implied by multiple participants as central to their experience of in-home caregiving while collaborating with other palliative services. Thirdly, *preparedness* was a code suggested by numerous participants as they described their readiness to become FCGs for a loved one at home while receiving formal palliative services. Some initial codes that captured this succinctly were – awareness of upcoming challenges, increasing family support, adaptation, routines/schedules, and organizing, structural and logistical changes to housing among many. Lastly, *resilience* was the practice that enabled immigrant FCGs to withstand, recover, and sometimes grow when faced with the adversities of caregiving; it was an active process of enduring and successfully coping. Some initial codes were – monitoring loved ones' needs, assessing the family members progress, learning and seeking education from palliative care HCPs to manage complex needs, and overcoming caregiving challenges.

These focused codes identified recurrent patterns and multiple layers of in-home caregiving that shaped immigrant FCGs experiences of EOL and their perspectives of the palliative

care services they received. As I worked through my analysis of my focused codes, I wrote informal analytic notes called memos. These memos helped me to develop my ideas, fine-tune my code names, engage critically in what the data was saying, and make comparisons about my codes and resulting categories.

Theoretical/Substantive Codes

Theoretical coding aims to integrate and solidify the analysis in a theoretical structure (Charmaz, 2014). Following the focused coding, *theoretical coding* is the next level of analysis that conceptualizes how the focused codes relate to one another and tell the story in a theoretical manner. The theoretical coding process revealed three main theoretical categories that emerged from the participants statements (1) Cultural Values and Norms of Caregiving (2) Caregiving as a Family Unit (3) Building Caregiver Resilience (Appendix E). These categories had sub-categories described below that fit and explained their distinctiveness.

The theoretical coding process aims to collapse the data from focused codes to theoretical codes in order to uncover the core process. *Maintaining Dignity in Dying* emerged as central to the experience of in-home caregiving by immigrant FCGs in collaboration with other palliative care services. Maintaining Dignity in Dying was relational as it revealed how participants built trust and created bonds that fulfilled caregiving expectations and honored their loved one's wishes. This core process (*Maintaining Dignity in Dying*) captured the complex features of the family immigrant caregiver experience of caring for their loved one at home.

Overarching Theory

This study's theoretical model was: *Immigrant FCG experience of caring for a loved one at home: A Relational Process of Maintaining Dignity in Dying*. This theory emerged through data

analysis and the constant comparative method of constructivist grounded theory. This substantive theoretical model (Figure 1) shows how the core process Maintaining Dignity in Dying unfolds for the immigrant FCG supporting a loved one at home.

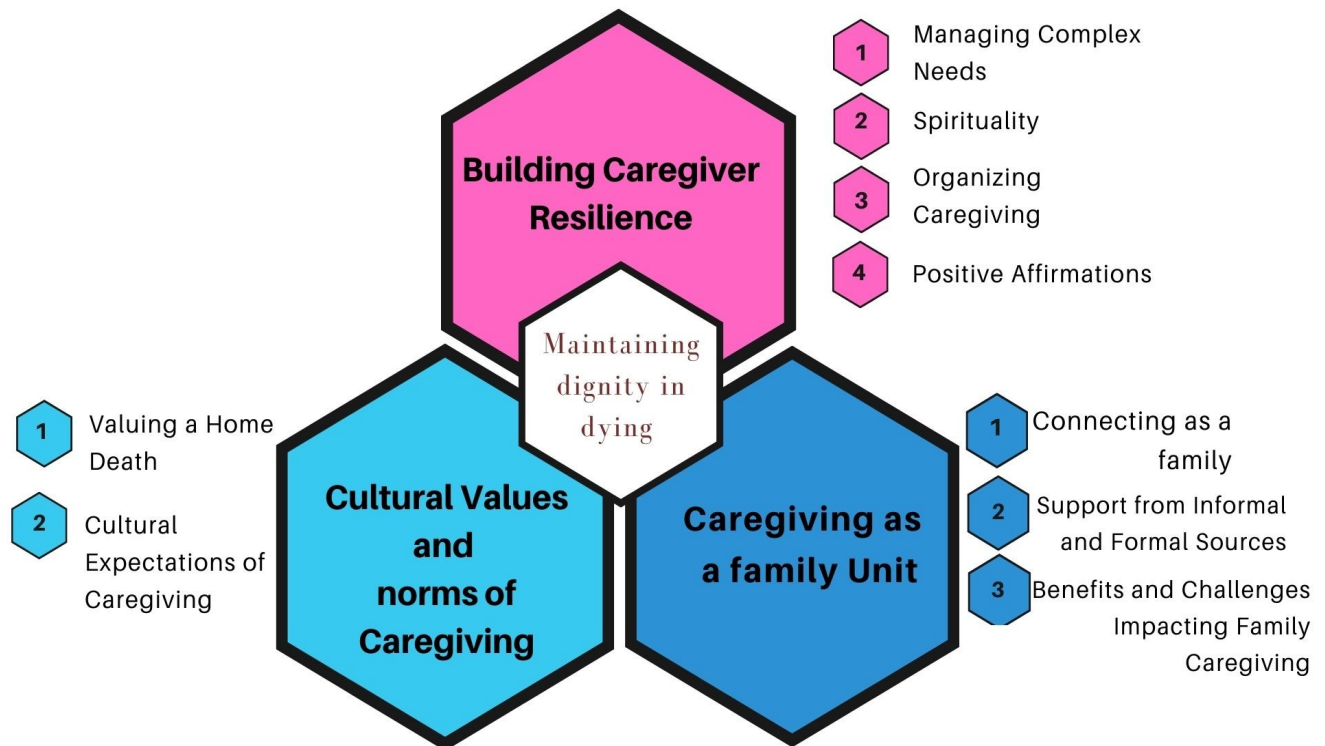


Figure 1. Immigrant FCG experience of caring for a loved one at home: A Relational Process of Maintaining Dignity in Dying.

The theoretical model aimed to understand meanings and actions of immigrant family caregivers as they cared for their loved ones at home. The theory conceptualizes the collective experience through the context of each family caregiver realities and social situations. This substantive

theory consists of a core or central process of *Maintaining Dignity in Dying*. Maintaining Dignity in dying in this study is viewed by all family caregivers as a purpose of their actions in caregiving. Immigrant family caregivers in this study spoke openly about being attentive to meeting the needs of their loved ones – involving comfort and upholding cultural values and beliefs, working together as a family unit and building resilience as caregivers so that they did their best to make sure that their loved one had quality end-of-life care. Maintaining Dignity in Dying is a belief that a loved one deserves to die in a dignified way at home. Dignity is reciprocal because it is nurtured and supported by the families through the attitudes and behaviors, communicated to their loved ones at the end of their lives. Immigrant family caregivers maintained and conveyed dignity when they assessed and monitored their loved one's condition holistically (physical, mental, emotional, spiritual) to ensure that they were comfortable. An overarching goal of the family caregiving experience was to enhance their loved one's quality of life at home with services offered by palliative care professionals. Family caregivers worked together with the health care professionals from palliative care to adjust formal services to fit the uniqueness of immigrant FCG-loved ones' situations. Family caregivers' cultural values and beliefs were central to caregiving decisions, allowing them to respect their loved ones, and family's wishes. Through unconditional love and respect for their loved ones, their family as a whole, and others who offered care to their loved ones, the majority of the immigrant FCGs maintained dignity in the dying and death of their loved ones.

The core process of Maintaining Dignity in Dying is relational because it fosters familial connections and interdependence while collaborating with palliative care services. Participants' trusting relationship with their loved ones enabled the possibilities for maintaining dignity and improved quality of living for both the family and their loved one. This core process acknowledges the multiple

realities of each immigrant FCG's situation, cultural values, and beliefs – inherent to a constructivist grounded theory approach. Finally, this core process of maintaining dignity in dying is foundational to a palliative approach and philosophy of care because it encourages the respect of participants' unique needs, experiences, and desires for EOL in-home caregiving.

Maintaining dignity in dying as a core process is conceptualized through the three major categories (theoretical codes) within this theory (1) Cultural Values and Norms of Caregiving, (2) Caregiving as a Family Unit, (3) Building Caregiver Resilience. Each of these three categories encompasses sub-categories that explain the properties of the categories and what constitutes the relationship to the process of maintaining dignity in dying.

The first category of the core process is *Cultural Values and Norms of Caregiving*. This category represents the cultural beliefs and ideologies that shape and influence the participants' in-home caregiving and utilization of other palliative care services for self and their loved ones. Cultural Values and Norms of Caregiving encompass two interrelated sub-categories: a) Valuing a Home Death and b) Cultural Expectations of Caregiving. The second category of the theory is *Caregiving as a Family Unit*, which consists of three sub-categories: a) Connecting as a family, b) Support from informal and formal sources c) Benefits and Challenges impacting family caregiving. Caregiving as a Family Unit is another pivotal element in the process where death is perceived as a family responsibility. The family unit as a whole directly or indirectly bears the responsibility for informal and practical support that makes dying at home possible. There is a familial readjustment to the declining health of a loved one and reorganization of family roles. Participants and their families rally formal support (palliative care services) and informal caregiving roles to optimize the living and dying experience at home. The last category is *Building Caregiver Resilience*, consisting of four sub-

categories: a) Managing complex needs, b) Spirituality, c) Organizing Caregiving, d) Positive Affirmations. Building caregiver resilience in this study is a complex and multidimensional concept crucial for managing caregiver burden among participants. Caregiver resilience helped immigrant FCGs deal with caregiving challenges while sustaining their capacity to care for themselves and their loved ones. Building caregiver resilience helped improve immigrant FCGs' confidence in their caregiving abilities while reducing their susceptibility to stress. Each category is now described prior to discussing the sub-categories that encompass the respective category.

Cultural Values and Norms of Caregiving

The cultural beliefs, attitudes, and characteristics of immigrant FCGs and their loved ones were recognized as prominent in shaping the caregiver's ability to sustain themselves during the challenging caregiving times. Immigrant FCGs spoke of their ethnic background, how they were raised, their religion and spirituality as crucial for day- to- day caregiving decisions. The participants' cultural heritage was influential on how they responded to informal caregiving challenges of their loved ones. In times of crisis, such as when the loved one's health significantly changed, culture was a source of shared strength and resilience for the individual immigrant FCG and their family.

For the entire sample of immigrant FCGs, keeping their loved ones at home was a "right and correct" choice – it met cultural and familial expectations of the caregiving process, including how EOL in-home caregiving care services were initiated and received. Culture influenced how participants and other family members defined in-home caregiving – forming the basis for a meaningful and purposeful EOL experience. With palliative care support, participants made keeping their family members home for end-of-life care worthwhile. There are two sub-categories in this category a) Valuing a home death and b) Caregiving as a cultural expectation.

Valuing a Home Death: A home death was in keeping with participants' needs and preferences of caregiving for their loved ones. All the participants were committed to reciprocating love with in-home caregiving, and to do so mean respecting the EOL wish of a home death for their loved ones. This was the case of Camille, for whom taking care of her husband at home for EOL was the only viable option because he had previously expressed a strong wish to remain at home. For her, a home death was valuable because it was a familiar environment for her husband and for EOL caregiving. Camille revealed this by saying:

there's no way for me to let my husband stay there [institution], as long as I can, I will keep my husband at home. The doctor said [you] cannot take him home once he is discharged because he has to go to [a] Long-term Care [facility]. But I said No, there's no way I can keep my husband [in a Long-term Care] except at home.

This quote revealed that the participant's priority for in-home caregiving and her commitment to maintaining dignity in dying for her husband was not feasible in long-term care or other institutions. The benefits of an accustomed environment coupled with the anticipated guilt associated with the placement of a loved one in institutions made in-home caregiving optimal for maintaining dignity of a loved one during EOL care.

Family caregivers discussed the importance of being constantly present and the family's ability to be fully involved in care as a necessary way to maintain dignity in dying for the loved one. For all participants, a home death was valuable because they had 24-hour access to their loved ones. This was particularly important because many of the participants' loved ones had previously voiced that they wanted to die at home surrounded by their family. This sense of duty and obligation to a loved one was entrenched in their cultural value system as immigrant FCGs and supported by their decision to offer

care at home. The inability to see and be present for a loved one as needed and feed them the food they are accustomed to was not possible in institutions and was a motivation in achieving death at home, as revealed by Nasa:

When the doctor told me in the hospital that we have to send her to the nursing home, I cried; I said no. We are not going to send her; we can take care of her at home. And she cannot eat the food herself. We have to feed her all the time. You cannot stay there [nursing home] 24 hours to take care of her.

Achieving a home death was valuable and beneficial because it meant participants and their loved one will stay in a familiar environment to experience dying. This provided some psychological benefits to participants and it was respectful of their loved one's wishes and attributes necessary for maintaining their dignity in the dying process. Glory had this to say:

I think there was a lot of benefit I feel like she was not ready for hospice because she could not be in that environment [institution], she did not like it there; she always wanted to be in the environment of [her] home.

Achieving a home death in conjunction with other palliative care services ensured the best possible outcome for participants in this study. Additional palliative care services made a difference in attaining participants' preferences of keeping a loved one's death in a familiar environment with constant access. Melissa recalled her mother-in-law's emotional response to dying out of her home, "I [will] die in this house" to a nurse who had suggested a nursing home in case her (mother-in-law) condition deteriorated. For Melissa, this statement was a clear indication of her loved one's wish for a home death "I know this [home death] is something that she wants. I know she doesn't want to go to a

nursing home". Also, a home death was psychologically valuable because it provided a sense of peace and control to EOL in-home caregiving, essential for maintaining dignity in dying.

Cultural Expectations of Caregiving: A home death was a cultural expectation for all the participants, requiring formal and informal support to make it happen. It was culturally relevant and expected for participants in this study to assume and not question if caregiving would be a part of their role as a family member. Caregiving was an expected part of life that was passed down from generation to generation in their culture. In this study, participants described it as a norm, they found ways to let their loved ones remain with them as a family and stay in their community. Immigrant FCGs and their families had to do whatever they could and use available services to provide in-home caregiving at all costs. The combination of informal caregiving and palliative care services was necessary because it allowed immigrant FCGs to embrace their cultural practices and rituals not deemed feasible in institutions. This was the case for Glory: "the decision [in-home caregiving at EOL] is culture-based and driven by how we are raised, my mom's wishes [was] that we take care of her at home, rather than taking her to any facility". Keeping their family member at home allowed them to fulfill the cultural expectation of being a caregiver and continuing to live with culturally specific rituals that are a part of their unique identities. For Melissa, it was essential to experience EOL in a location where participants and family could meet cultural expectations of caregiving like daily devotional prayers of her mother-in-law, vital for spiritual well-being: "She is always there with prayers; we have devotional gatherings every night when we just sit around and we say prayers together".

Immigrant family caregivers were very clear in describing the commitment, passion and ingrained beliefs, asserting that caregiving was a part of who they were as individuals and as a family.

Families valued caregiving as part of their shared identity and belonging – this meaning offered me as researcher a way of understanding their experience.

These cultural expectations of in-home caregiving were a combination of some Canadian values and some other international cultural identity. In this study, participants alluded to the fact that institutionalizing a loved one for EOL caregiving was part of a Canadian value in particular and a Western value in general. Other of such Canadian and Western values that were embedded in the data was diversity, independence, and autonomy. Many participants had some of these values in combination with cultural values common in other countries. This was evident by participants' obligation to their cultural expectations of in-home caregiving and Canadian values of independence and autonomy. In her reflections on reasons for in-home caregiving, Camille highlighted these two values (autonomy and providing in-home caregiving) in different statements. Independence and autonomy were evident in her decision to keep her husband home despite medical recommendations to send him to a long-Term Care facility:

The doctor said that once he's discharged, I cannot take him home because he has to go to long-term, but I said no. There is no way I can keep [in Long-Term care] my husband excepts to be at home. That's the last thing I will do; I will get my husband home.

As her reflection continued, Camille's commitment to cultural expectations of in-home caregiving was evident in a subsequent statement.

It is because that's the way we were raised (to provide in-home caregiving), we love our family. So that's why back home we never send our family to a nursing home, we take care of them whether old, young we are is taking care of each other, no matter what you do take care of family.

The above statements revealed two cultural influences at play in her decisions to keep her husband home for EOL. Through self-determination, participants made autonomous healthcare decisions embedded in a cultural view that in-home caregiving was an expectation and a duty. Such views were respectful of their loved ones' wish EOL and essential for a dignified death.

Participants frequently expressed that religious rituals, food preferences, and communication styles as integral parts of this sub-category. Many participants agreed certain religious rituals such as prayers were compatible with in-home caregiving. For Glory, it was important for her mother, who was a devout Sikh, to be still able to do her prayers at a particular time: "her routine was like that she wakes up at five in the morning she does her prayers." The same was the case for Nasa, for whom in-home caregiving was culturally compatible because of her mother-in-law's EOL spiritual needs: "Oh ya, she is very spiritual. We have a 24-hour tape going for her [in her] bedroom and she was listening to [her] prayer. Twenty-four-seven, this tape recorder was on". Having a sense of control of EOL in relations to spiritual rituals allowed immigrant FCGs and their loved ones to find meaning in informal caregiving. Spiritual practices provided familiarity to immigrant FCGs and their loved ones in an unfamiliar situation of EOL in-home caregiving.

Food preferences were an expression of cultural identity for many participants. Food types and cooking styles were a way of preserving their culture while receiving at EOL. Formal palliative care services complement in-home caregiving so well because it allowed participants and their loved ones to receive necessary EOL care at home, where their cultural identity was preserved and expressed partly through food. Camille acknowledged the importance of food in her choice of letting her husband stay at home by saying, "he [husband] wants to eat 'normal' food. He does not like the food there [hospital]". Nasa corroborated this as she said "and over there in a nursing home, or hospital they are not giving the

same food which she [loves to] eat".

In each of the above participant statements, it is evident that "cultural values" significantly influenced the choice of caregiving at home with supplemental palliative care services. These services made it possible for the loved one to be at home where they were able to maintain their cultural practices at EOL. Participants' awareness of their cultural values and how it shapes caregiving at home helped maintain dignity in dying for their loved ones.

Caregiving as a Family Unit

Most participants were part of a larger family unit that worked together to improve the outcomes of in-home caregiving. In this study, the family unit was the collective of family members who were involved in the support of EOL caregiving of the dying relative such as a 1) spouse, 2) children or grandchildren, 3) extended family. The family unit served as a foundation for participants' emotional and physical support during caregiving. Family units profoundly affected participants' caregiving decisions and the implementation of caregiving practices and routines. Many EOL caregiving decisions were made with the family unit as the priority. The data revealed that although individual family caregivers had different roles, discussions about the caregiving experience were often made in light of the family unit context. Members of the family unit were involved in the caregiving experience directly or indirectly. Thus, the stress associated with keeping the dying loved one at home and the accompanying caregiver burden of the participants, affected the entire family unit. The study data revealed that formal palliative care services were key in uniting the varying perceptions of the family unit members and ensuring their perceptions fit together for maintaining dignity in dying of their loved one. These services supported the family unit by taking up vital caregiving responsibilities so that the family unit can focus on informal caregiving. Examples of such support to family unit in this study

included decision making; symptom managements; monitoring the patient; coordinated referrals for other appointment; logistical changes to participant's homes to facilitate caregiving, and emotional support. This category highlights the importance of the family unit's combined caregiving efforts for an optimal EOL experience at home. The following sub-categories are a part of Caregiving as a Family Unit: a) connecting as a family, b) support from Informal and Formal Sources c) Benefits and Challenges Impacting Family Caregiving.

Connecting as a family: In-home caregiving allowed participants and their families to be intentional about spending time together meaningfully. In this study, keeping a loved one at home for EOL was a turning point in the caregiving process, facilitating emotional and physical bonding between family members – critical for maintaining the dignity of a loved one at EOL. This sub-category encouraged family members' interdependence on each other while simultaneously channeling resources necessary for creating a supportive environment for an optimal EOL experience. Jasmin revealed the importance of family connections in the care of her grandmother:

We are like a super tight-knit family. We just felt like keeping [at home] my grandma as close to us as possible would be the best for her. Our psychologists and our psychiatrist doctor also agreed that the only reason she is as healthy as she is today is family care and family love.

Connecting as a family was evident from the data as all the participants approached in-home caregiving as a collective. The use of the pronouns "we" and "us" by all participants signified a familial connection and was a combined effort attentive to the quality of life for their loved one. Immigrant FCGs connected with each other by sharing caregiving tasks, creating memories, reminiscing the past and anticipating grief together. This sub-category was particularly significant in in-home caregiving experiences because the time with the terminally ill family member was limited. In-home caregiving

was generally helpful and supportive of familial bonding, an attribute crucial for maintaining dignity in the dying of a loved one. Melissa and her family were aware of mother-in-law's declining condition, noting the importance of bonding with limited time available: "we know for sure she is probably not going to be with us much longer. So, we are keeping mom comfortable, and we are trying to be there for her for whatever she needs materially, physically and spiritually".

However, there were moments identified by one of the participants that showed how the intensity of caregiving fostered an antagonistic relationship between family members. This antagonism was evident in situations where caregiver burden was overwhelming for participants, affecting familial relationships. Nasa confirmed this when she revealed how caring her mother-in-law affected her relationship with her family:

the family dynamics changed; it changed dramatically because I was the one taking care of everyone at home. I was the one making meals for family members, and I was the one taking care of my husband.... so I was neglecting my husband in one way, his care was compromised, and he was not happy with whatever he was getting, not happy with the food. So, there was some tension in the relationship.

This participant went on to reveal that she had to hire private caregivers to assist with the caregiving, in addition to the palliative care support provided. The palliative care professionals were instrumental in facilitating the hiring process, providing the immigrant FCG with support. Nasa revealed this when she said

You have to go through the [hiring] process, you have to take the classes and then you have to give them a company and name [of people] when we are ready to hire these people.... Every month you had to work, then you have to hire your own accountant, the accountant has to

make that much. We have to pay her (employee) much all [money] and everything. That's very expensive [but] we have to do [it].

The study data also revealed meaningful moments for participants and their families to connect as they experienced anticipatory grieving. In these moments, participants used the phrases like “being there” or “being present” as a symbol of this connection. Anticipatory grief in this study referred to participants preparing for their loved one’s end of life or a major loss in their loved one’s abilities. Some participants experienced anticipatory grief with a combination of hope that death meant their loved one will no longer suffer from pain and discomfort. Family connection was expressed in both small and big ways, some eventful and others simple. Jasmin and her family had deep connections with her sick grandmother in small yet meaningful ways by making her smile:

when we do ask her like if she loves us or something like that, she will smile and then she will say yes, and her just giving us the smallest smile at the smallest affection is her being there for us.

For Glory, her brother's wedding during in-home caregiving was an event of meaningful connection as a family. Planning and executing a wedding event together with her dying mother and her family was memorable, as she detailed after her mother's passing:

She was always there[planning]; it was not like she was not left out. It was not like the mom is missing to make those important decisions in her son's wedding. She was the one telling me what to do, even though I was the one physically doing everything, prepping everything for the wedding, but she was the one telling me what to do. So, I always felt the directions were coming from her.

Physical connection was difficult for family members who did not live geographically close to

the participants and their loved ones. Connecting at a distance occurred for most immigrant FCGs with extended family members abroad or still in their countries of origin. Long-distance familial connection was limited to emotional support enhanced by modern communication tools like social media. Melissa and her mother-in-law received emotional support from Iran via callings applications like WhatsApp and IMO: “she has a cell phone, and she has WhatsApp and Imo, so she goes and sits in the living room and calls people”. Other family members made sacrifices and traveled from their country of origin just to be near to connect to the family as a unit and to be with the dying family member.

Fulfilling the final wishes of their loved ones no matter how difficult the process was revealed the commitment of keeping the family connected. Respecting a loved one's last wishes was a symbolic and significant family process to be connected to one's homeland for participants in this study and other extended family members. Participants respected their loved one's last wish of a home death and sometimes this included a cultural and familial expectation to die and be buried in their (loved ones) countries of origin. For Amanda, respecting her father's last wish to return to his country of origin (the Philippines) and die there was an event necessary for familial bonding for herself and her extended family members abroad. This required her family and the assistance of palliative care services to help plan international travel during the COVID-19 pandemic.

His[father] wish is to go back home to spend the remaining life that he has with the grandkids, and one of my brothers and, of course, relatives of ours back home, but because of the pandemic, it is hard for us to go right now. The nurse says if we plan to bring him [back] to go to do it now, but it is tough, we are thinking of bringing him back home in April or May when things [pandemic] settle. That is my wish, and I am crossing my fingers that that will happen. It is not in our control, right?

The extra support provided by palliative care services facilitated participants' and their loved ones' need to connect with other family members home or abroad- an attribute that maintains dignity in dying.

Support from Informal and Formal Sources: In considering how they managed to continue caregiving at home, immigrant FCGs reflected on the importance of the role that both informal and formal caregivers from palliative care services played, to help them continue to provide the best possible caregiving environment. All participants in this study anticipated caregiving challenges and had strategies in place to address them. Immigrant FCGs as the experts of the EOL care of their loved ones enhanced and guided decisions for the best caregiving strategies by support from family members, friends, faith and other palliative care service providers. The utilization of formal services was prominent among other support strategies to be diligently employed by immigrant FCGs. This sub-category consists of participants' interdependence on others (formal and informal support) for an optimal caregiving experience.

Informal supports encompassed the networks of assistance that existed in the participants' lives, such as other family members and friends who encouraged, supported, and guided them during in-home caregiving. The study data revealed different informal support attributes acknowledged and received by participants during in-home caregiving including emotional support, physical assistance, and spirituality. For some immigrant FCGs, informal support also came from their countries of origin, requiring international travel to meet physical support needs. Melissa depended on her sister-in-law for informal support: "she does everything I do, she does probably 60% of it 70% when she's here, and she does not even let me do [anything] I have to say okay you know what I want to do this." Having other family members around for support offered valuable respite and was momentous for working together

as a family unit maintaining the dignity of their dying loved one. For Amanda, even though she was the primary caregiver, her brother provided his house for a better in-home caregiving experience and quality of life for their father: "I am in my brother's house, but I am the primary caregiver to my dad, but my brother and my sister-in-law are also helping". With the likelihood of death of the loved one, there was new meaning to the informal support networks for participants and the assistance their loved one received. Participants and other family members began to experience anticipatory grief as a result of the losses which became present in their dying loved one such as: the loss of abilities, loss of independence, loss of cognition, and loss of identity among many others. This anticipatory grief revealed how urgent and crucial informal support was in maintaining dignity in participants' loved ones.

Participants also expressed gratitude for formal support from the many Health Care Providers (HCPs) from palliative care services such as nurses, doctors, dietitians, occupational therapists, and personal care workers for their encouragement, non-judgmental attitude, and compassionate approach to caregiving. Data revealed that many participants were happy with the formal support they received. Jasmin reported that palliative care was instrumental in addressing pain symptoms for her grandmother by saying: "palliative care came to help dress her and help just take care of her and control for symptoms and just try to make her as comfortable as possible".

Amanda was surprised by the type and amount of support offered to supporting her dying father. She instantly made comparisons with what she could have experienced in her country of origin and was grateful with the opportunities that living in Canada had afforded her, her family and their dying relative. She articulated this in the statement below

I'm glad, like he's [father] here in Canada. In comparison to health care way back home [Philippines] there at home is not good at all, compared to here, because here I didn't know that you can get some help from the Alberta Health Services free plan I heard I was talking to Lisa last week, I'm so impressed. And I can't believe that we can get all this kind of stuff. So, yeah that', I'm happy because my dad is here, and he is [being] taken good care by me, my family, and help from, from the Alberta Health Services.

Melissa had mostly positive experience with formal support but also expressed her dissatisfaction with the hygiene of some palliative care services staff in a statement later in the interview. She first acknowledged the help of palliative care by saying: "it [in-home caregiving] has been very hard, but with palliative care health professionals coming into our house and they are very careful, and they are very loving". She then went on to address her dissatisfaction by saying:

We had a few people that came on I understand they go to different places. Once there was a lady that came and I was downstairs I heard the bell. And I realized that mom had opened the door and I knew that the caregiver was coming in at that time. I came upstairs probably about three four minutes after they had already gone upstairs. I could smell the body odor from downstairs to the second floor where she was and most of the times they smelled really bad and I mentioned this to her to their company and I said, the people who come to give you a shower [should] actually think about their own hygiene first. So I told them to, you know, I honestly don't want this.

Stella was appreciative of a system that could provide relief when she needed to recover from surgery: "because of my surgery, I have to put him in [respite], but only because of my surgery. Carewest told me that he could do some exercise at the same time because all the time he was using a

walker". This caregiver relief was initiated and coordinated by PHC services.

It was important for participants to acknowledge the need for formal and informal support. Informal support allowed close friends and other family members to provide encouragement and caregiving relief to participants. Glory revealed this in her statement about informal support she gets from her family "there was my brother, there was my father, there was my sister-in-law, so it was four of us taking care of my mom; emotionally supporting and encouraging each other and providing breaks". Informal support served as essential safeguards to protect and promote the quality of life for participants and their loved ones during EOL caregiving. These safeguards are based on established relationships participants and their loved ones had with friends, families, and neighbors. These individuals were aware of participants' history, the choice for in-home caregiving, and their aspirations for EOL care. Formal support complemented this informal support for a better in-home caregiving experience and outcome. As discussed by Glory, the nurses help and education was valuable "the nurse comes to my house to help me with my mom's care or teaching me and my family members, how to take care of her". This harmonious relationship was critical for maintaining the dignity in dying for the terminally ill family member. For Amanda, this harmonious relationship between formal and informal care was vital for the care her father received "he [father] is being taken good care of by me, my family, and help from, from the Alberta Health Services.

Benefits and Challenges Impacting Family Caregiving: This sub-category assessed the combined effects of informal in-home caregiving and palliative care services on the family unit. It was evident from participants' responses that in-home caregiving was a daunting task with both positive and negative effects on the family. In-home caregiving was frequently viewed in a family context, suggesting a spill-over effect of its benefitting and challenging attributes to the family unit.

Participants weighed caregiving stresses on the family unit by assessing the changes in familial behaviors and attitudes towards one another as they supported their loved one at EOL. Common positive effects mentioned by participants on the family were: new relationships, having a sense peace and comfort, and family teamwork. On the contrary, caregiving stress encapsulated the negative effects of the entire process on the family. The ups and downs of caregiving were discussed by all immigrant FCGs. Participants reported how other family members were overwhelmed by in-home caregiving; how they had put many important aspects of their lives on hold to in order to provide support to a loved one. This was the case for Glory and her brother

There were a lot of things we I put on hold I wanted to do Master's so I had to put my education on the side. My brother wanted to go to a different job. He wanted to become an accountant and he wanted to go work in accountancy job but because they work for like 12 hours in a day, so he didn't do the job

Achieving a home death was psychologically beneficial for the family unit-many participants experienced a sense of comfort and peace in having constant access to their loved ones. Amanda stated: it is good to see him here, and it is easy on our [family] hearts as we see our dad, every minute, every day [and] that he is still here. So, it makes us [family] feel more at peace, rather than putting him in a place that we cannot see him if we want to see him.

For Glory, in-home caregiving had psychological and social benefits for her and her family even after her mother had passed away. Glory's perspective was in tune with her mother's needs and desires for EOL at home – necessary for a “good death” and the coping of the family unit after death:

mentally or psychologically, I can see that we [family] have peace of mind with what we did (in-home caregiving). If I did not do those things at that time, I would probably be regretting right now –

like why was I wasting time? And I could have spent that time with her. So I tried to make every minute count.

In-home caregiving encouraged families to work together and grow together as a unit. This study highlighted how family teamwork at EOL built trust, opened new lines of communication that focused on the common goal of providing a conducive environment for an optimal EOL experience. Participants indicated that in-home caregiving fostered new relationships between family members that were purposeful and fulfilling. The data was rich with families working closely together to ensure the well-being of the sick member and other relatives at EOL. Glory supported this by saying: "for example, if I am here with my mom, I make sure that my father is resting or doing his own thing so he gets his time away so he will have his own life on the side." This teamwork guaranteed familial and emotional support of members of the family unit. Family members were able to listen to each other and problem-solve collaboratively while supporting one another to deal with the stress of keeping a dying loved one at home. There were positive aspects of caregiving, such as familial altruism and adaptation to the caregiving situation – creating a sense of calm among family members. Jasmin's statement revealed how providing care at home has made her family understand better the needs of her grandmother and became more compassionate:

we slowly learned to be more compassionate and we understood her (grandmother), and it has brought us a lot closer because we have learned to give each other space when needed, but we've also learned to be more compassionate towards each other.

On the contrary, there were adverse effects of in-home caregiving that affected the family dynamic – these were common in all participants' families and frequently concurrent with the positives of in-home caregiving. This was evident in the spilled-over effect of the emotional stress of their loved

one's disease conditions and caregiving burdens on the family unit. The breadth of spill-over effects was vast, with nuances that affected each member differently. The spill-over effect was a factor of the unique relationships participants and their loved one shared with other members of the family unit which were meaningful in their own rights. Glory corroborated the spill-over effect in her statement:

I felt like while it was not only my mother who was suffering from her disease condition, I felt like the well-being of all my family members was important. Everyone needed rest sometimes because everyone got tired. Mental health was something that everyone had a problem with because everyone was suffering emotionally.

For most participants, in-home caregiving were beneficial in being attuned to the dying person's wishes, but also the concerns of the caregivers – improving participants' and their family's preparedness to support EOL care at home. EOL in-home caregiving afforded the family unit time and space to stay connected in a way that supported dignity in dying for their loved one. Palliative care services considered the family as the focus of care, and helped the families anticipate the daily the unfolding of events and caregiving tips that would be helpful to their loved one with support extending beyond death and into the bereavement period. The family unit could experience a "good death" that was respectful of their loved one's preferences, minimize suffering, and maximize the benefits of in-home caregiving. In-home caregiving in conjunction with Palliative care services was essential for providing critical psychological support to participants, their loved ones, and their families. With the family as a unit of care, in-home caregiving services could improve family relations with in-home caregiving; thus, maintaining dignity for the dying family member.

Building Caregiver Resilience

Building Caregiver Resilience is the last category of this study's core process – it is elucidated by data showing participants' ability to adapt and overcome stressful situations associated with in-home caregiving during EOL. Resilience was vital for immigrant FCGs to bounce back from in-home caregiving challenges like disappointments, sadness, exhaustion, and powerlessness. It was necessary because most FCGs had not been formally trained to undertake the caregiver role. In this study, many factors enhanced caregiver resilience; the few highlighted by the coding process were learning new skills, established routines, social support networks, and spirituality. Building Caregiver Resilience consisted of four sub-categories: a) Managing Complex Needs, b) Spirituality c) Organizing in-home caregiving, and d) Positive Affirmation.

Managing Complex Needs: Participants' awareness of the complexity of their loved one's condition and the process of dying at home was a precursor to this sub-category. Participants described how the deterioration of their loved ones' physical, social, psychological, and spiritual health contributed to the complexity of caregiving. It is important to note that part of this sub-category included participants' acceptance of the illness reality, the impending death of a loved one, and the inclusion of formal palliative care services as a new and necessary strategy to strengthen resilience. Managing complex needs fits the broad category (building caregiver resilience) because it equipped participants with the knowledge and skill set to support in-home caregiving. The study data revealed palliative care services played a significant role in supporting participants' resilience by empowering them to identify significant changes in their loved ones and manage these changes to the best of their abilities. For example, Glory and her family were taught on how to identify changes in wound size of her mother's cancerous tumor as she said this:

They [palliative care HCPs] are always educating us to notice any wound changes like if the wound is increasing in size, I used to call the nurses at Tom Baker's cancer that the wound size is increasing or there's different type of drainage coming out of her wound. So we use, we had all the contact numbers where to contact and where to go and seek help.

Significant changes in this study identified as “defining moment(s)” were influential in the unfolding of the caregiver experience at EOL – guiding caregiving decisions including the support from other family members and the use of palliative care services. Defining moments was denoted by participants as event(s) that led to a major shift in the caregiving condition of their loved ones. Frequently, participants associated defining moment(s) to a deterioration of their loved one’s condition; however, there were a few instances of improvements in relation to defining moments. For some participants, defining moments were observable and identifiable signs; other times, it was based on intuition from the participants and palliative care HCPs. It is important to note that defining moments were very important for participants even in the absence of independently observable determinable events. Defining moments gave a name to an event(s) that was influential on the course of in-home caregiving for the immigrant FCG and their loved one. These defining moments were significant symbols (symbolic interactions) during EOL in-home caregiving which shaped participants’ perception of dignity of their loved ones and how to maintain it. Participants and their loved ones did not just encounter a set social reality but rather had to define for themselves (social interpretations) what EOL in-home caregiving will look like. Caregiving then unfolded based on their interest which was primarily determined by what the patient wants and what to do to make it happen. Examples of such symbols (events) were terminal diagnosis, family decisions, Goals of Care Designation (GCD) among others. These defining moments highlighted the role symbolic interactions in guiding the course of

EOL in-home caregiving, particularly the implementation of caregiving measures that enhanced a dignified experience for their loved ones. For example, Jasmin recalled the disease timeline of her grandmother highlighting the defining moments like diagnoses and worsening conditions as an antecedent for palliative care

my grandmother was diagnosed with Alzheimer's in 2012, and it slowly started to progress and I think it was 2018, She got diagnosed with breast cancer, and then her tumor started to grow a lot more recently and then so we needed the help of palliative care to come help dress her and help just take care of her and control for symptoms and just try to make her as comfortable.

Jasmin revealed that another defining moment in the course of in-home caregiving was the resurgence of her grandmother's aggressive behaviors. This was a complex situation that was addressed with the support of palliative care services "when she was aggressive, it was quite hard because she would not ever listen to us for a while; for example, and she would go to the washroom everywhere in the house."

For Glory, a defining moment was a conversation she had with her mother during an emergency room visit, a conversation that significantly influenced events during EOL. Her mother stated her wish to see the wedding of this participant and her brother- events that were very important to the participant and her loved one

She (mother) was sick one time and in emergency [and] she was not able to talk at that time because of trach [ostomy]. So I asked her what do you want in your life? She told me that she wants to see me and my brother get married.

Glory and her brother were able to get married with their mother participating to the best of her

ability. These defining moments allowed participants to focus on caregiving strategies that made it possible for wishes to come true. These defining moments had significant bearing on how EOL in-home caregiving evolved in ways that were respectful of the wishes of the participants and their loved ones hence supporting and maintaining dignity in dying. As previously stated by this participant, these defining moments helped her cope with her mother's passing because she could look back on her in-home caregiving experience with no regrets

Melissa listed defining moments for her mother-in-law as she said: "she had a few fractures on her back. She has a severe osteoporosis. So she keeps breaking her ribs, cracking the ribs or so. It's been just a few years now that she is worse." Nasa was aware of a general decline for her mother-in-law which she revealed as a defining moment – her mother-in-law's health did not deteriorate quickly but just did not improve: "she was comfortable during her time with me, she was not getting better, but she wasn't like uncomfortable. She was fine symptomatically but she just died comfortable". Glory was able to identify some defining moments that were improvements in her mother's condition with the assistance of palliative care services:

One and half year of going through cancer, her trach [ostomy] came out, she was able to breathe through her nose. There were a couple improvements in her weight- it was continually increasing it was not decreasing anymore. She was able to walk more than usual. She was more energetic, she used to laugh and when the trach [ostomy] came out she was able to talk to us. And she was able to breathe normally than what we have seen before.

These moments revealed participants' awareness of care complexity through noticeable changes in their loved one's unique illness trajectory. A collaborative approach with palliative care services supported timely assessments of defining moments at home while implementing strategies to manage

them. Defining moments improved the participants' resilience by supporting adaptations to in-home caregiving challenges necessary to allowing them to maintain dignity in dying.

Palliative care services equipped participants with the skills to manage complex situations associated with in-home caregiving. Two obvious empowerment strategies used by palliative care HCPs were: 1) changes in the caregiving environment and 2) participant education. All the participants had to make structural and logistical changes to their homes to accommodate in-home caregiving in conjunction with palliative care services. This involved dedicating a room for EOL caregiving, creating access to dedicated room, putting side rails, putting handles around toilet seats, raising toilet seats, arranging a cart for medical supplies, among many others. Creating a conducive home environment facilitated caregiving in a familiar physical, social, and cultural setting. For Glory, some structural and logistical changes in her home were reflected in her statement: "we had oxygen setup, suction setup, infusions setup, then changes in her bedroom and then making sure that she had all the things available upstairs". Jasmin corroborated the importance of having structural and logistical changes by saying: "little things like we had to get a new bed for her, one that would rise, so we could feed her in bed if needed. In her bathroom, she just had another stool – a shower stool". Also, the home was a conducive place for the practice of social, spiritual and cultural acceptable practices as already described in first category (Cultural Values and Norms of Caregiving).

Caregivers needed education on managing complex needs of their loved ones – this included specific information related to each individual's EOL needs. Learning new skills was how participants became empowered to be informal caregivers. Skills in managing their loved ones' complex needs and how to access other services in Alberta Health Services (AHS) were of critical importance. Immigrant FCGs discussed the importance of a collaborative relationship with palliative care HCPs for skill

acquisition and skill improvements. Glory revealed how education improved her family's abilities to manage tube feeding and tracheotomy care of the mother:

There was a person who taught my dad how to give a feed to my mom at home, how to clean it, how to make sure it's working properly, where to call if the feeding tube is not working, if there's any problems with the feeding- how to fix those troubles...they (tracheotomy clinic) taught us what the signs to look for, where to keep the emergency supply stock for trach and all the things to do if the tray comes out.

Newly learned skills made immigrant FCGs confident and competent to manage care and advised others informal caregivers on the best care practices for their loved ones. This process started with an awareness and acknowledgment (defining moments) and then actions for an optimal EOL experience. Becoming empowered with skill sets needed to keep their loved ones at home was essential for building participants' resilience for in-home caregiving.

Spirituality: This sub-category was related to building caregiver resilience because it gave home caregiving meaning and purpose for many participants – a fundamental element of EOL experience. For the majority of the participants, it was expressed as religion and religious rituals. Participants' beliefs represented in this study were Christianity, Sikhism, and Baha'i. This sub-category showed the personal connection participants and their loved ones had with a transcendence – the ways in which they expressed reverence. It is vital to note that even though all the participants in this study ascribed to an organized religious group, spirituality could occur both within and without traditional religions. Spirituality was vital for coping with illness, and caregiving while maintaining dignity in dying. Jasmin summarized how spirituality was vital for herself and her family's resilience:

so we go along to the Sikh Faith, and a firm belief in our religion is -do not focus on the afterlife

and focus on the present. So I feel like that has helped a lot to not be anxious and not overthink about what is going to happen afterwards; rather focus on the now and focus on making her happy and making her, and giving your best to her.

For Melissa, her Baha'i faith was essential in maintaining dignity in dying by keeping her older mother-in-law home for caregiving purposes: "the Baha'i faith, which is our religion, there is very important to pay homage to your parents; you need to take care of your parents. That is something that God has ordered for you to do". For Amanda, her catholic faith was critical in keeping optimism and hope for her father's health condition during caregiving at home: "We are Catholics; we pray, we know that prayers and praying can help my dad, especially now in his condition."

Spirituality was an intrinsic and essential component of the home caregiving experience of participants in this study. Religious rituals and practices improved participant's resilience by providing hope and optimism in the face of difficulties and uncertainties. Spirituality provided value by preparing participants for anticipatory grief while readying their loved ones for transition to the next phase. The data from this study suggested that while palliative care services did not actively promote or counteract the spirituality of participants and their loved ones, taking off some of the physical and emotional burden associated to caregiving meant that the immigrant FCG and their loved ones could focus more on spiritual well-being during the dying experience. Caregiving at home in conjunction with palliative care services ensured participants' rights to practice rituals important to them and their loved ones were guaranteed, thus maintaining death with dignity.

Organizing Caregiving: Organizing caregiving gave participants a structure to manage expectations, enable better decision-making and guaranteed consistency. Routines became particularly important in organizing in-home caregiving, as was recalled by all participants, indicating how

essential they were to building resilience. By being predictable and repeatable, routines provided immigrant FCGs with a framework and direction of operating. All the participants had an established routine that ensured the inclusion of palliative care services, and cooperation of other members of the family. Organized caregiving reduced the power struggles between participants, their loved ones, other family members, and HCPs. Participants created routines that were inclusive of all the things important to their loved ones and themselves, scheduling appointments and meetings around times that lead to minimal disruptions. These routines appeared to be controlled mostly by the participants and were frequently based on the best interest of their loved ones. Palliative care professionals were very supportive of families setting their own agendas and routine, working with the proposed schedule to provide optimal formal support.

Stella supported her father's routine by saying: "he had a schedule initially when I was working, but if I need some additional days I took vacation, because I have to go with him to all his appointments, he cannot go by himself to this". Amanda revealed she had to move her father to her brother's house because his routine required someone to always be at home

Me and my brother talk about moving my dad to stay with them, because there is always someone in this [brother's] house. That's why he ended up living with my brother. Yeah we've made arrangements so that somebody is with him all the time. And I am the primary care [and] because my time at work is flexible and I can come here at any time. So that's the plan. That's why he is leaving here.

This sub-category allowed participants to schedule appointments and referral of their loved ones at times that was conducive for them – a strategy that enhanced adherence to treatments proposed by formal services. Peculiar to established routines was the ability for immigrant FCGs to have a

caregiving-rest balance or respite, to occasionally relieve them of the daily burdens of caregiving. This was the case of Glory, who said: "for example, if I'm here with my mom, I make sure that my father is resting or doing his own thing, so he gets his time away, so he will have his own life on the side."

A caregiving-rest routine provided immigrant FCGs with a sense of organization and reassurance during in-home caregiving. This study data suggests that a focused, organized, and detailed management plan of in-home caregiving were important for participants' resilience in in-home caregiving. This was demonstrated by how established routines also guaranteed flexibility by almost all of the participants, giving room for adjustments if necessary. This was the case of Camille, who said this about her routines:

It [routine] is very flexible because I don't want that if he doesn't feel like being changed in the morning [I must to do it]- unless he wets himself. However, even eating sometimes, when I came in, [and] I just want to hook up the [feeding] machine [and I say] you have to get up to get ready [but he says] I want to sleep so [I say] Okay, I will wait until when you're ready. And I will take a nap. So at least for two hours, and then check again by 10, sometimes 1030, then he is ready to get up.

Established in-home caregiving routines were not synonymous with the idea of restriction or loss of free will. Instead, it provided a sense of focus, helped eliminate distractions, and reduced the power struggle between participants and their loved ones while ensuring cooperation – all crucial in maintaining the dignity in dying.

Positive Affirmation: Participants used positive affirmations to foster an optimistic mindset and minimize negative feelings of in-home caregiving. A mindset change inspired participants to show up for in-home caregiving and palliative care service collaboration with an attitude focused on

improving the EOL experience at home. Often related to the spiritual dimensions of palliative care, positive affirmation creates possibilities for self-empowerment with the beliefs of motivation and hope. Positive affirmations motivated and enhanced participants' resilience and fortitude when interacting with their loved ones, other family members and palliative care HCPs. With positive affirmations, participants overcame negative self-sabotaging thoughts of in-home caregiving. Melissa confirmed this by saying:

I love the part of my faith [that] says unity of mankind is number one priority for us, and I think of this [in-home caregiving] not as a favor to my mother-in-law and I think of it as a way of life.

Her faith was a consistent source of encouragement to achieve desirable behavior when confronted with challenging situations of caregiving. The fact that she described caregiving as "a way of life" changed the perspective from caregiving as a regular chore to caregiving as a duty of care to her loved one.

Camille often reflected on her negative emotions before engaging in challenging caregiving tasks: "When I come from work, and when I see [that] he messed up [himself] and stuff, I just take a deep breath and then do my job." After reflecting on the caregiving task, Camille could empower herself and re-channel negative thoughts of the situation to more positive thoughts before engaging in caregiving. This specific behavior management technique used quickly and quietly prompted Camille to stop in her tracks, acknowledge her emotions, and refocus on the duty of care. Participants who implemented this technique have conditioned themselves to behave in a specific manner in the face of challenging in-home caregiving situations. Positive affirmations are flexible and creative, with the primary goal of providing care with the appropriate mindset.

Immigrant FCGs also received positive affirmations from external sources such as other family members, the palliative care professionals and also from their loved ones. They used feedback to obtain positive affirmation from outside themselves – acknowledging positive changes in their loved ones and their families. These experiences were valuable as it consolidated their decisions to keep a loved one at home. This was the case of Stella who revealed that her father enjoyed staying at home while receiving other palliative care services:

He was enjoying because he saw big, big differences between health care back home and healthcare here and even, like last time, care with people. He told me, I'm like a president, I have personal room... he really enjoyed life in Canada as well.

When their loved ones were unable to verbalize feelings, participants based these affirmations on intuition and observed behaviors and improved moods evident by smiles, boosts in eating, and physical activities among many. For Camille, she noticed her husband and daughter were happier with in-home caregiving:

He (husband) seems like he is happy [with in-home caregiving and PHC service] because the only place that he likes is his home, the only place to like to sleep is his own bed. She (daughter) seems she is happy [with in-home caregiving and PHC services]. She is comfortable.

The positive affirmation also came in the form of participants minimizing caregiving tasks and caregiver burden to limit or change negative emotions. Jasmin said, "I would say [in-home caregiving] is not a burden, but it was emotionally taking a toll on all of us." This sentiment was similar to what Melissa said about her mother-in-law "she is like a second mother to me I do not know, maybe I have a problem, but this [in-home caregiving] is very easy." All these statements were concurrent with many participants putting some aspects of their lives on hold to meet the needs of their loved ones staying at

home while receiving other palliative care services.

Positive affirmations turned feelings of frustration and isolation into constructive thinking vital for attaining and maintaining dignity in dying at home.

Summary

The theoretical model (Figure 1), as described and explained in this chapter, depicts the core process of *Maintaining Dignity in Dying* by participants. The major categories of the underlying process were Cultural Values and Norms of Caregiving, Caregiving as a Family Unit, Building Caregiver Resilience and their related sub-categories which provide insight on the core process for immigrant FCGs. Through data analysis and interpretation of the categories and sub-categories, a co-constructed theory emerged – *Immigrant family caregiver experience of EOL in-home caregiving: A Relational Process of Maintaining Dignity in Dying*. The theory was interpretive and open to new meaning for each immigrant FCG's unique circumstances. The feelings of loyalty, trust, and cooperative attitudes within the family group was a prominent and shared attributes among all the sub-categories of this substantive theory. In the next chapter, I will examine these categories further and discuss them in relation to relevant literature. This is done to establish a better understanding of how the study's findings fit with what is already known about the in-home caregiving experience of immigrant FCGs. Implications for nursing practice and future research based on the findings will also be discussed.

Chapter Five: Discussion and Conclusion

Family caregivers (FCGs) play an essential role in keeping a loved one at home for EOL for a better quality of life (QOL), well-being, and quality of care of a terminally ill loved one. For many FCGs and their loved ones, the home remains an ideal place to die because of the numerous physical, mental, and emotional attributes of a familiar environment. The informal caregiver role is critical given the increasing reliance on de-institutionalized care for hands-on care, spiritual and emotional care, and care coordination (Hollander et al., 2009). The Canadian Hospice and Palliative Care Association (CHPCA) (2013) also confirmed that most Canadians (75%) want to die at home, while CHPCA (2017) revealed that if the death occurs in the home, Canadians (90%) are more likely to say that the setting matched the family member's preference. Immigrant FCGs form a significant subset of these FCGs who would prefer the home setting for a loved one. This subset (immigrant FCGs) was the main subject of this study considering the barriers that they face – cultural, communication, socio-economic status, healthcare system structure, and immigrant knowledge (Ahmed et al., 2016). There have been a limited number studies that focus specifically on the immigrant FCG experience of in-home caregiving.

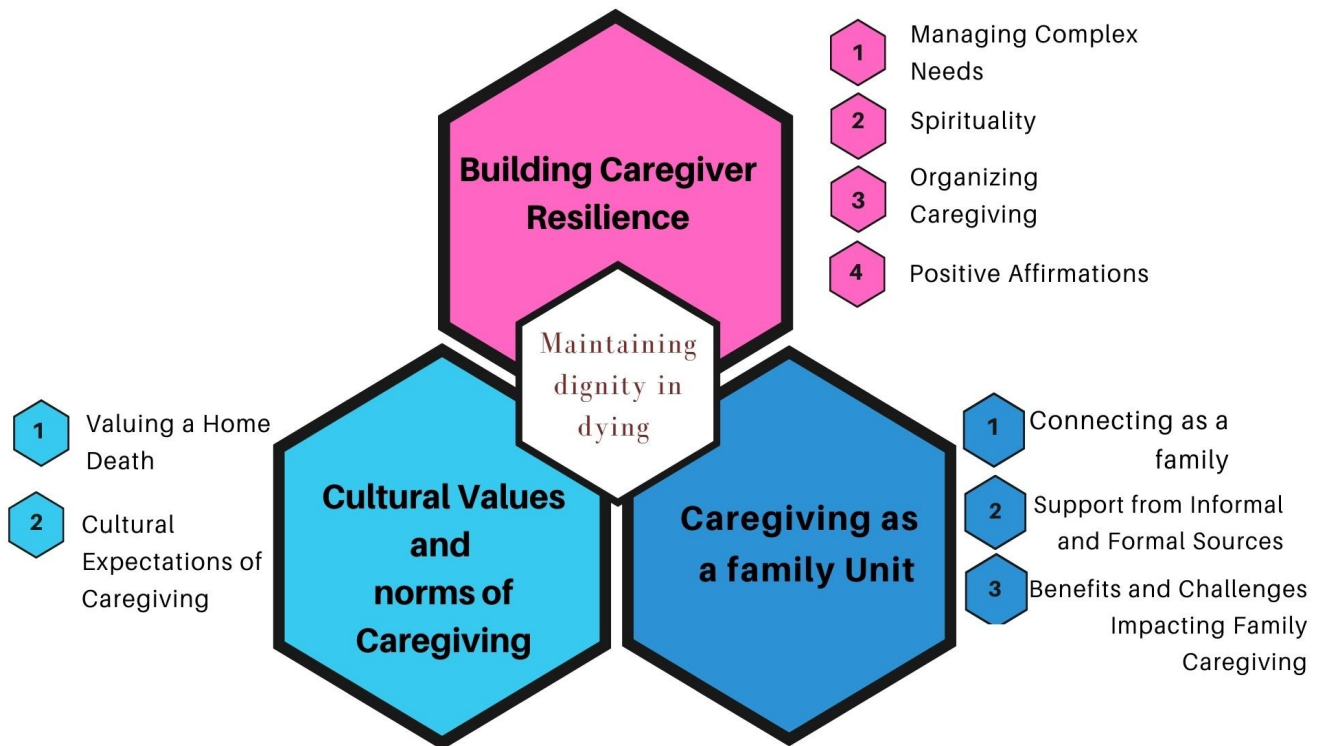
In many developed countries, the number of informal caregivers from minority ethnic groups is rising as the demographic profile of these populations' ages with increasing proportions of older people (Lievesley 2010). This was consistent with the ethnic diversity as witnessed by a recent 2016 Census showing the immigrant population of Canada to be 7,540,825 and that of Alberta to be 845,215 (Statistics Canada, 2018). Of this population will emerge immigrant FCGs possessing similar experiences of EOL in-home caregiving that are interrelated in some sense and distinct in others. This study aimed to generate a substantive theory that would explain the experiences of immigrant family caregivers in the Calgary Zone. In this chapter, I re-visit the theoretical model, my research question and findings that ensued in relation to relevant research. Finally, I discuss implications for nursing

practice, education, and research.

Re-visiting Theoretical Perspectives of Immigrant FCG

The theory, *Immigrant family caregiver experience of EOL in-home caregiving: A Relational Process of Maintaining Dignity in Dying*. (see figure 1 below), describes the experiences of immigrant FCGs supporting a loved one at home. The core process is underpinned by three conceptual categories: *cultural values and norms of caregiving*, *caregiving as a family unit*, and *building caregiver resilience*. There are essential sub-categories that make-up each category. The sub-categories of valuing a home death and cultural expectations of caregiving are featured in the first category of *cultural values and norms of caregiving*. Connecting as a family, support from informal and formal sources, and benefits and challenges impacting caregiving are the three sub-categories that exist in the category of *caregiving as a family unit*. Lastly, the sub-categories of managing complex needs, spirituality, organizing caregiving and positive affirmations were unique to the category of *building caregiver resilience*. As participants navigated the process of maintaining dignity in dying at home, these categories and their subsumed sub-categories begin to highlight their experience of in-home caregiving. If any of the sub-categories are removed, the immigrant FCGs experience of in-home caregiving might be sub-optimal; consequently, they might not attain desirable levels of maintaining dignity in dying.

Figure 1. Core process of Immigrant FCG experience of EOL in-home caregiving



The Core Process: Maintaining Dignity in Dying.

Cultural Values and Norms of Caregiving

In this study, the initial considerations of the FCGs in upholding the core process is *cultural values and norms of caregiving* which describes what shapes and influences participants' decision to keep a loved one at home for EOL and how palliative care services enhance this choice. Cultural values and norms of caregiving as a category is informed by beliefs and traditions significant to the immigrant FCGs' including the reception and level of involvement of palliative care professionals. For the immigrant FCGs, keeping a loved one at home for EOL was part of the expectation of the "right and correct" choice for EOL care. Cultural heritage guided in-home caregiving decisions and expectations. Participants' descriptions of these sub-categories underpin the importance of fulfilling cultural and familial expectations of EOL in-home caregiving.

This category examines the cultural influences that support immigrant FCGs keeping their loved ones at home for EOL. This present study reveals the centrality of cultural heritage as participants consider providing informal care at home. These cultural heritage can be advantageous or disadvantageous to the immigrant FCG depending on the circumstances. Kirby et al. (2018) purported that culturally and linguistically diverse populations' palliative care experience may entail additional complications around language and cultural values, including barriers to communication and isolation from the broader community. Participants in this present study needed EOL in-home caregiving support that reflected their preferences regarding the discussion of diagnosis and prognosis, communication preferences, family involvement, and decision-making. For example, some participants prioritized a family decision-making model for EOL care decisions, and others deferred decisions to their palliative care HCPs. For some participants, cultural expectations of EOL caregiving did not resonate with the Western biomedical notions of patient-centered care. In their study, Kirby et al. (2018) revealed that culturally diverse populations have an expectation of more traditional forms of home-based care for the

dying – provided by informal caregivers. This meant that institutionalized palliative care was difficult to comprehend for several participants, thus establishing EOL in-home caregiving as a cultural expectation.

Cultural Sensitivity

Participants in this present study served as critical guides to cultural sensitivity at EOL by highlighting beliefs, values, traditions, and practices that honor their loved ones. Informal caregiving became essential because it provided a context in which cultural values and beliefs shaped decisions around caregiving and the use of formal support interventions (Giunta et al., 2004). During the interviews, participants shared multiple accounts of values and norms of caregiving, revealing directly or indirectly that in-home caregiving was a cultural expectation warranting the use of any means necessary to make it happen. Many participants ascribed these cultural expectations to their cultural upbringing, their views of family and the familial role in supporting a dying loved one and their religious backgrounds. This was evident in the fact that some participants lived in the same household where multiple generations were present to provide physical, emotional, and spiritual support to the terminally ill relative. Participants' data in this present study revealed palliative care services were mostly beneficial to the immigrant FCGs and their loved ones because it usually incorporated what matters most to them for EOL. Givler et al. (2021), asserted that beliefs, experiences, and values of the patients and their families improves the quality of the medical care provided. Participants in this present study placed value on a duty of care to a loved one and put in place strategies to meet these obligations – a significant part of which was in-home caregiving. Findings also revealed participants' appreciation of the combination of in-home caregiving and complementary Palliative care services, often associating it with a better experience for EOL. With the help of palliative care professionals, participants were able to manage behaviors and distressing symptoms of their loved ones making EOL

in-home caregiving experience less challenging. Palliative care programs have also been shown to improve quality of life, reduce physical symptoms, reduce psychological distress, and improve accessibility to formal care providers (Melin-Johansson et al., 2010). Integrating cultural values and norms associated with caregiving optimized the effects of palliative care interventions, resulting in family-centered EOL support, relevant and meaningful for the immigrant FCGs-loved one dyad. For example, some participants reported that their decision to keep a loved one at home was a cultural expectation, consistent with their upbringing, family values, religion, and spirituality.

Chow et al. (2010) study of FCGs in the United States of America described the uniqueness of each FCG showing that race and ethnicity are associated with different patterns of support (formal and informal) received among family caregivers. Their findings suggested that minority caregivers have a more diverse group of extended helpers than do non-Hispanic Whites and those minority caregivers reported a desire or need for varying types of formal support services despite similar usage and lower burden scores as compared with White caregivers. Williams et al. (2016) did a similar study among Canadian caregivers concluding that there were multiple and overlapping axes of diversity (such as age, ethnicity, employment status, geography, social connectedness, and immigrant status) that influence the caregiving experience. These studies provided some understanding of intersecting and overlapping factors that influence immigrant FCG experience of in-home caregiving. The uniqueness of the immigrant FCG-loved one dyad in this study was evident in demographics, housing conditions, cultural expectations of caregiving, disease process, family support, EOL wishes and preferences, among many others. Despite the distinctiveness of caregiving situations, the *value of a home death* and the *meaning of cultural expectations of caregiving* were common among all the participants and were critical for participants' adaptation to a caregiving role and their collaboration with palliative care services. The outcome of this collaboration was a culturally appropriate in-home caregiving evident by

spirituality, ritual practices, food preferences, and language and communication preferences, connections to family and friends, and socialization. These shared values and beliefs were observable at multiple levels with immigrant FCGs, their loved ones, and their families. Despite the differences in what the caregiving expectations were, Maintaining dignity at EOL was the ultimate goal for all participants. It was the overarching theme of the purpose of participants' experience – respecting their loved one's wishes and fulfilling caregiving expectations.

Home Death

Valuing a home death was central to participants respecting their loved ones' EOL wishes, an expectation entrenched in their cultural upbringing and personal obligations to caregiving of a loved one at EOL. A home death allowed participants to collaborate with palliative care professionals to address the physical, psychological, and spiritual needs for themselves and their loved ones in a familiar space. Some participants had the contacts of palliative care HCPs to ask questions and have access to other services when they required it. Also, many participants highlighted the benefits of education and mentorship received from palliative care HCPs to manage significant changes during EOL in-home caregiving. This collaboration ensured productive communications and coordination of the patient's care between immigrant FCGs and palliative care HCPs. It was an opportunity for FCGs to have inputs and have them incorporated by palliative care team and vice versa. Communication was a critical aspect of EOL caregiving as many participants acknowledged the need for a trusted translator or a medical interpreter to assist with language impediments. Research indicates that HCPs tend to report greater quality of communication with patients and less medical errors when trained interpreters facilitate dialogue (Flores et al., 2003). Ahmed et al., (2016) suggests the use of creative ways of reaching out and educating immigrant groups need to be explored so they become aware of available

resources. By missing clues or misunderstanding a patient's cultural viewpoint, it is possible for HCPs to unintentionally offend, or place the diagnosis, adherence to treatment, and health outcomes at risk.

There are various reasons that individuals choose a home death. At the personal level, individuals choose a home death was because they can have family nearby in familiar, comfortable surroundings (Canadian Virtual Hospice, 2019). At the systems level factors such as the quality and cost of end-of-life care in the acute care setting influenced decision making for home deaths (Gallo et al., 2001). These reasons are in the context of the de-institutionalization of health systems to favor community services (Giesbrecht et al., 2012) with home care becoming one of the fastest-growing healthcare system components (Romanow, 2002) – including a home death. Valuing a home death was a prominent piece of the cultural expectation among participants and their loved ones. Cultural expectations and a duty of care to a loved one made a home death intentional and purposeful for participants in this present study, with many expressing a "feeling of peace" with their decisions (Participant 7). Tang (2000) purported that a home death gave FCGs a greater chance to control their environment, more autonomy and privacy, and a sense of normality. A home death allowed participants to include aspects of their international cultural experience that were not feasible in institutions, such as spirituality, language, and food preferences. Giuntoli and Cattani (2012) studied expectations of caregiving, and categorized them into two areas – abstract high standards and pragmatic expectations. *Abstract standards* included high standards of good practice, cultural understanding, and responsiveness to individual expectations. In contrast, *pragmatic expectations* were culturally specific expectations of practices that immigrant FCGs and their loved ones associated with maintaining dignity. In this study, the abstract and pragmatic expectations were nuanced, particularly as participants' primary focus was on maintaining dignity in dying, not categorizing and compartmentalizing caregiving expectations. This nuance was evident as participants had abstract standards of what was appropriate,

and acceptable for maintaining dignity of their loved one such as communication and trust and at the same time dealing with practical demands of the physical and emotional needs of EOL in-home caregiving such as dressing and praying with a loved one.

Foundational to achieving a home death as a cultural expectation is the importance and meaning of *home* in EOL in-home caregiving for the immigrant FCG and their loved one. Seto et al. (2013) described home as a "place of belonging," (p. 650) while Zweig et al. (2009) described the home as part of a person's identity. The home became a place for participants to negotiate the difficult transitions from life to the death of a loved one. Part of this negotiation involves using palliative care services to complement informal in-home caregiving for a dignified death. Gomes et al. (2013) found that when someone with an advanced illness receives palliative care, their chances of dying at home more than double. In EOL, the home is more than just a physical location of caregiving; but a place where emotional connections are made with a dying loved one and other family members. This was supported by Gillsjö and Schwartz-Barcott (2011), who said the home is not just a house; it is a place, relationship, and experience. The experience of EOL at home adds a new dynamic to the meaning of a home – a place that prepares it for the transition of a loved one to death. Tryselius et al. (2018) summarized the importance of a private home at EOL labeling it a central position in processes of palliative care and dying. The findings from this study reveal the importance of immigrant FCGs' identity in supporting a terminally ill relative while receiving services and retaining connections to family, friends, and the community. The preference of home for participants in this study often pointed to the idea of "dying in place" (Degenholtz et al., 2004, p. 116) – the concept that allows death in a familiar environment (habits, routines, memories, and daily activities) and with the company of family members. Rando (1984) asserted that continued contact with those who have been and are part of their lives reaffirms to dying individuals that they still are the same people they always have been. As such,

the familiar environment of the home and the constant supporting relationships confirms the continuing identity and importance of the dying person to participants. This is consistent with earlier research showing that feeling attached to one's residence and community is an essential factor in the receipt of health services (Dale et al., 2012) and is positively linked to identity and feelings of control (Theodori, 2001). This highlights the sentimental and relational attributes of a home (Gillsjö & Schwartz-Barcott, 2011) making it meaningful for participants to maintain dignity in dying of their loved ones.

Valuing a home death rightly serves as a precursor for achieving death at home – an essential determinant of the overall quality of life for participants and their loved ones. A departure from the expectations of in-home caregiving and a home death can be unsettling and indicate to participants' loved ones that they are already perceived as socially dead. Kralov (2015) identified three characteristics of the definitions of social death as a loss of social identity; a loss of social connectedness; and losses associated with disintegration of the body. Each of these suggest that the concept of social death represents a compromised well-being of the terminally ill relative that may influence the way they are perceived either directly or indirectly. Regardless of the loss of identity of a loved one, participants' in the present study were still determined to treat their loved ones with love and dignity irrespective of their state of well-being. Part of this involved responding to the call of duty by keeping their loved ones at home for EOL even when care was complex and challenging.

Despite the intense consideration of 'duty' to a loved one and the cultural expectations at EOL, the burden of achieving a home death was compounded by the unmet needs in service delivery systems (Aoun et al., 2005; Jo et al., 2007). In this present study, palliative care service delivery depended on participants' available resources, informal support, public health restrictions (due to the COVID-19 pandemic), cultural and social preferences for EOL. Palliative care put in effort so that these multiple facets of EOL caregiving could come together to support participants and their loved ones in a way that

was mindful of the structural, cultural, and social dimensions needed to maintain dignity in dying. However, even with all the services offered, some participants still struggled to keep up to the demands of care for their loved one, citing limited amount of support received from formal and informal sources. According to Dying in America (2015) failures to coordinate care, disruption in care planning, and medication errors were all are implicated in poorly managed transitions between care settings, including between hospitals and private homes. The challenges in care coordination highlighted the importance of communication for the optimization of support for a home death.

In their study, Gomes and Higginson (2006) identified factors affecting a place of death; a) factors related to illness, b) individual factors, and c) environmental factors. The factors relating to illness dealt with the type of disease, the length of disease and the functional status of the dying person; the individual factors dealt with demographic variable (income, social class, marital status) and personal variables (preferences); environmental factors dealt with use of home care and the social support received from informal caregivers and extended family members). This model hypothesizes that EOL in-home caregiving was complex and affected by multiple variables.

Caregiver burden

In this present study, participants identified being at serious risk for physical, social, and financial burdens resulting from caring for a dying family member at home. Physical challenges included chronic fatigue, physical exhaustion, sleeplessness, burnout, and deterioration in their health (Candy et al., 2011; Corà et al., 2012). Emotional problems such as helplessness, uncertainty, and hopelessness (Robinson et al., 2014) affected EOL in-home caregiving while social challenges included restrictions on time and freedom, disruption of personal routines and leisure activities (Woodward et al., 2004). Some participants highlighted some social burden of in-home caregiving, listing activities that they enjoy but could no longer engage in such as social events, traveling, education, job

opportunities. Other factors included financial problems, isolation, and occupation-related problems in the phase of caregiving (Hudson et al., 2011) and role conflicts associated with having to balance the needs with financial challenges (Wolff et al., 2016). These in-home caregiving stressors suggested that participants spent a significant amount of time focused on caregiving rather than talking, sharing, or sitting quietly with the dying loved one -a possible deviation from the initial intent of in-home caregiving.

Caregiver burdens are either objective or subjective. Brink (2009) described *objective burden* as the quantity of time performing a caregiving task, the type of tasks performed, and the resources (physical and financial), while *subjective burden* refers to the caregiver's emotional impact. Both often occurred simultaneously among the present study participants as a byproduct of cultural expectations and individual traits of EOL in-home caregiving. However, in this study, it was challenging to distinguish between culturally based expectations and individual traits and how they influenced in-home caregiving. This was so because participants' personal traits and attitudes towards EOL caregiving were shaped by culture, influencing how they saw themselves as individuals within the larger context of the family unit and the society. The lack of this distinction in this study and previous studies can result in an over-emphasis of cultural factors or individual differences while ignoring the interaction between them. Research suggests that many shared experiences of caregivers across all ethnic groups and caregivers from diverse ethnic groups can identify both positive and negative aspects of their role (Scharlach et al., 2006). Participants in this study identified many factors that affected EOL in-home caregiving such as language barriers, transportation challenges, coordinating with families abroad, coordinating home transitions, managing appointments, coordinating with formal palliative care services. For example, a participant faced challenges organizing for their loved one to travel abroad sooner rather than later to visit other family members before he passed. Some studies related

these FCG burdens to caregivers from racial and ethnic minority groups, enlisting structural barriers to service utilization, including inadequate transportation, insufficient knowledge about services, cost of services, language barriers, negative prior experiences with services, and lack of culturally sensitive services as part of caregiving challenges (Damskey, 2000; Dilworth-Anderson et al., 2002). As such, ethnicity, immigrant status, and culture may also play a significant role in caregiving stress and coping.

Caregiving as a Family Unit

This category examines the dynamic nature of caregiving by a family unit over time, as members work together to provide an environment supportive of in-home caregiving. Caregiving as family unit resonates with the Family System Theory (Bowen, 1960s) purporting that one's family unit or family center overall has a profound impact on their emotions and actions. Participants in this present study viewed EOL in-home caregiving as a family event with varying degrees of positive and negative effects on its members. The larger family unit experienced a spillover effect of caregiver burden based on the level of physical and emotional involvement in EOL caregiving. The spillover effect results from caregiving or simply caring about others, or a combination of the two (Wittenberg et al., 2019). While the literature tends to focus on primary caregivers, other members of the family unit both provide care and experience spillover effects of illness (Bobinac et al., 2013), hence the importance of assessing in-home caregiving effect on the entire family unit. Caregiving as a family unit is critical because family functioning can become a significant factor in determining the quality of EOL care rendered by informal or formal caregivers. Stajduhar et al. (2008) reported that the family unit was vital because it offered caregivers practical hands-on help and a support system available in a non-judgmental way. Part of this was finding new ways to connect as a family during in-home caregiving and rallying support (informal and formal) to enhance EOL in-home caregiving. Findings revealed that spill-over effects were both beneficial and challenging on the family unit. Some participants identified

benefits such as becoming closer as a family unit, spending quality time with a dying relative and fulfilling caregiving expectations while many identified caregiver burden as the main challenging spill-over effect on the family unit. Kristjanson and Aoun (2004) corroborated this as they identified the benefits of palliative care on the family unit – a time of closeness, reflection, and enhanced family interactions, and identified challenges as burden of the illness communication difficulties, and dysfunctional family patterns. The present study suggested adjustments in family unit structure to maximize benefits and minimize challenges of the dying experience for participants, their loved ones, and the larger family.

Familism

Valdivieso-Mora et al. (2016) define familism as a cultural value in which a higher emphasis is placed on the family unit in terms of respect, support, obligation, and reference. Familism is a concept that places value of the family over self and can affect EOL in-home caregiving perceptions and practices. In this study the importance of symbolic interactionism is amplified by connecting it to the concept of familism. It was expressed in varying ways by participants and dependent on the caregiving circumstances. It supported the use of spiritual, cultural, and familial symbols among others to foster a family unit's caregiving obligations to a terminally ill loved one. It appeared to bring participants closer to self, their loved one, palliative care HCPs and other family members. In fact, it was a common theme among all the sub-categories of caregiving as a family unit.

This concept has been largely explored among Hispanics like Mexicans, Cubans, Puerto Ricans, and Central and South Americans (Cortes, 1995; Fitzpatrick, 1971; Marin, 1993; Mindel, 1980; Rogler & Cooney, 1984; Sabogal et al., 1987). Most of these studies placed a cultural lens to familism, frequently describing it as a culturally grounded way of valuing and prioritizing family over self. However, more recent studies have explored familism among other ethnic groups (Rozario &

DeRienzi, 2008; Schwartz, 2007). Historically, Sabogal et al. (1987) identified three dimensions of familism which were relevant to the present study: (a) familial obligations, that is, the perceived obligation to provide material and emotional support to the members of the extended family; (b) support from family, which is the perceived support from relatives to solve problems; and (c) family as referents, which is the perception of relatives as behavioral and attitudinal referents. Familism supports the idea that obligations to a dying loved one changes as a natural part of family life. The changes that accompany EOL in-home caregiving offered benefits such as connecting and bonding in as a family and challenges such as the stress associated to caregiver burden.

Familism was important because it made EOL caregiving intentional and purposeful by giving the family unit something to look forward to while keeping members accountable to each other. Familism in this present study highlighted the centrality of the family unit in terms of feelings of loyalty, reciprocity, and love during EOL in-home caregiving. Participant data revealed that this concept was a multidimensional construct composed of core values of familial interdependence and obligations to an ill relative. This resonated with a significant part of the literature purporting attributes of familism such as strong family identification, attachment, mutual support, family obligation, and familial interconnectedness (Almeida et al., 2009; Lugo et al., 2003). Inherent to familism is the view that family members are interconnected, making it appropriate for in-home caregiving to be viewed as a whole rather than individual elements. The existence of an emotional bond and a sense of belonging suggest that the family unit has a unique role in the in-home caregiving of their loved ones. In this study, one outcome of this concept was families organizing themselves to carry out the daily activities of EOL in-home caregiving. This study revealed that a significant factor of caregiving as a family unit at EOL revolved around the form of relationship and social responsibility the caregiver has to the care recipient. For example, 6 out of the 7 participants interviewed felt the obligation and responsibility to

care for their loved ones at home because of familial expectations. Brink (2009) found that a home death was a prominent benefit of familism, associating it (home death) to a caregiver's ability to continue providing care. As such familism became the primary attribute that portrayed the relationships between sub-categories and how they affected each other to achieve the intended out of EOL in-home caregiving – maintaining dignity in dying. Familism was crucial for participants and other family members to establish a loyal and reciprocal relationship with the ill relative. It aligned with the cultural expectations of in-home caregiving and made participants and their loved ones feel loved and supported. The present study revealed that family unit members connected with others and palliative care professionals to share caregiving tasks, create memories, reminisce the past, manage symptoms, and anticipate grief. Familism was subject to cultural values and expectations needed for a richer understanding of how participants and their loved ones were supported at EOL caregiving. This concept had a substantial proportion of both positive and negative outcomes that caregivers and family unit's experience had for a sense of familial obligation and belonging. The results were positive effects of in-home caregiving on the family unit, such as new relationships, peace and comfort, and family teamwork. Other studies have highlighted the positive caregiving outcomes on family caregivers, such as reduced mortality and better well-being (Brown & Brown, 2014), personal growth experience, and a better dyadic relationship (Mavandadi et al., 2014). On the contrary, connecting during EOL in-home caregiving can negatively affect the family unit, such as substantial reorganization or disruption of the family system and increased possibilities for family conflict (Kramer et al., 2006). Family units must find purpose and meaning by having a common goal of in-home caregiving so that they can be united in ways needed for the attainment of dignity in dying for their loved ones. Familism was an expression on the philosophical underpinning of this study's methodology – social interactionism. It had implications on perception and practicalities of the core process of this study and on the family unit in

general. Hence, philosophically, familism as a concept permeated many of the existing sub-categories of this study with varying degrees of influence.

Connecting as a family frequently manifested as physical and emotional bonding was subject to the amount of time participants had left with their loved one. Findings revealed participants' bonding with their loved ones, other caregivers (formal and informal) was important for a dignified death for their loved ones. Participants' perceptions of the limited time they had with their ill family member had a significant effect on familism as expressed by the family unit. Many participants viewed the act of dying at home as an opportunity for intentional bonding enhanced by their constant presence and complete focus on what mattered to their loved ones. Kristjanson and Aoun (2004) argued that the family unit must confront shifts in their understanding of the meaning of life and relationships as they come to recognize the terminal endpoint of the loved one's illness. The realization that time is limited with a terminal illness increases the urgency for both the terminally ill relative and family members to say final goodbyes and to try to make amends, if necessary. This realization also creates a window of opportunity for people to make time in their busy lives to focus on the relationship with the terminally ill person through their participation in final conversations (Keeley, & Generous, 2017).

Communication at EOL

Communication (verbal and non-verbal) becomes an essential part of the main category with the potential to profoundly impact the EOL journey. This notion was supported by Keeley and Generous (2017), who revealed that communication at the end-of-life could help decrease individuals' fear of the death process and uncertainty surrounding death. Effective EOL communication is focused on understanding the ill relatives' values, care preferences, and a preparation for death that will lead to a plan of care that is congruent with expectation of the family unit. While some participants were comfortable talking about death, others struggled with having conversations about death and dying. It is

also important to note that the decision not to talk about death did not mean the participants were in denial. Many studies have highlighted the importance of final conversations and its role in enhancing connections in the family unit – which include all interactions, verbal and nonverbal, that the family unit has with the terminally ill from the moment of a terminal diagnosis to the point of death (Keeley, 2007; Keeley & Generous, 2017; Keeley et al., 2014). This communication can facilitate connections as a family via dialogue regarding the needs and desires of the terminally ill relative and other family members related to EOL in-home caregiving. It supports and encourages connections as a family earlier in the in-home caregiving journey, enabling the family unit to have a better EOL experience. This present study highlighted instances where final conversations were valorized by participants and their families. Final conversations were memory creating moments, in some cases “defining moments” the were sources of consolation and peace after their loved ones had passed away.

Building Caregiver Resilience

This category described how participants in this present study developed their ability to withstand, recover, and sometimes grow when faced with adversities associated with EOL in-home caregiving. This study revealed that participants could adapt and cope at varying degrees no matter how tumultuous external events or inner feelings of EOL in-home caregiving were. Although resilience can be thought of as a personality trait and outcome, it is commonly understood by scholars to be a dynamic process that encompasses positive adaptation in the face of significant adversity (Allen et al., 2010; Luthar et al., 2000). It is thus likely that immigrant FCGs’ abilities to be resilient or act resiliently in the face of EOL in-home caregiving stress, burden, and burnout are also shaped by socio-environmental contexts. Luthar et al. (2000) reported that resilience is a highly complex process simultaneously influenced by the individual and by the broader socio-environmental context in which they are situated. This confirms the association of EOL in-home caregiving resilience to multiple

factors, indicating the multidimensional nature of resilience. Donnellan et al. (2015) used the varied definition of resilience to identify criteria for its existence – 1) there must be a significant challenge, in this case, EOL in-home caregiving; 2) there must be no obvious sign of (di)stress; 3) maintenance of a life of meaning and satisfaction (a sign of bouncing back); 4) active participation in life (a sign of managing) and current life must be seen as positive (a sign of adaptation). This category appreciated the above criteria for this present study as it revealed participants' capacity to prevent or overcome damaging effects (physical, emotional, and financial stress) associated with EOL in-home caregiving. It also captured the importance of understanding EOL resilience in the context of individual immigrant FCGs and their family circumstances, social position, expectations, and environmental possibilities. Goldzweig et al. (2013), in their research concluded that promoting a resilient coping style significantly reduces emotional and physical demands involved in caregiving for families. Considering the consistent overlaps in the sub-categories and multiple variables associated with “building caregiver resilience,” it was wise to consider each sub-category separately for conceptualization.

Resilience and Managing Complex Needs

Managing complex needs (first sub-category) emerged as a critical component necessary to build participant's resilience as it restored balance and harmony when they encountered an increase in their loved one's caregiving needs due to an increase in complexity of the condition. According to Donnellan et al. (2015), FCGs are more likely to be resilient when they are knowledgeable, supported by family members, and can have access to support services. This was evident as participants in the present study did not exist in isolation but interacted with their environment; drawing on informal and formal support to enhance resilience in EOL caregiving. Informal support constituted families and friends who offered social support that facilitated the building of participants' resilience necessary to manage complex needs. In times of crises, participants could turn to other friends and relatives for managing complex in-

home caregiving circumstances. For example, one participant had relatives from Iran come to help out with caregiver burden she was experiencing while another participant had to move her father to her brother's house for constant supervision. Eisenberger (2013) in his review of social support, defined it as having or perceiving to have close relatives who can provide help or care, particularly during times of stress. Other studies have highlighted the importance of using "perceived social support" because of its ease of measurement and evidence that it is a better predictor of mental health than other measures (Dour et al., 2014; Friedman, 2011). Findings suggested social support was multi-dimensional as participants received support that was distinct yet interrelated. Ong et al. (2018), in their study, found that the level of perceived social support mediated the significant association between resilience and caregiver burden. Informal caregiving in this study had a combination of tangible and intangible social support available to participants through the provision of goods, services, or other concrete ways of enabling resilience building. Southwick et al. (2016) differentiated the facets of social support to include: a) structural social support (the size and extent of the individual's social network, frequency of social interactions); b) functional social support (the perception that social interactions have been beneficial in terms of meeting emotional or physical needs); c) emotional social support (behavior that fosters feelings of comfort leading the person to believe that he or she is loved, respected, and/or cared for by others); d) instrumental or material social support (goods and services that help solve practical problems); and e) informational or cognitive social support (provision of advice or guidance intended to help individuals cope with current difficulties). Participants showed that having social support was beneficial in handling the stress associated with EOL caregiving. A majority of the participants got relief from other family members or friends in times of stress, with some requiring international travels to make this happen while another participant had to plan a funeral of their loved one abroad. For some participants, social support was found in the family unit structure with the ill relative living in same

house often with multiple generations present. Reblin et al. (2015) revealed that FCGs dealing with more challenging issues, such as ongoing unresolved pain or complex family dynamics, may require more support from health care providers than other families. With more significant external resources, such as broader formal support networks and social networks, participants can potentially cope better with setbacks, solve problems, improve self-esteem and even manage health problems that arise from EOL in-home caregiving. These social supports can foster resilience building and ensure that participants can continue to provide care for complex conditions while maintaining their well-being.

Formal support was instrumental in developing resilience, more so because of the palliative care services involvement in the support and management of complex dynamics for participants and their loved ones. The present study revealed collaboration between palliative care professionals and participants in the planning and managing complex needs related to in-home caregiving. According to Foley (2005), informal care providers' most expressed needs include psychological support, information, specific skills to provide appropriate care, assistance with household duties and daily living, and respite or relief from caregiving responsibilities. The family-centered approach by palliative care professionals involved engaging with FCGs to set up goals that strengthen individualized and culturally responsive capacity. This study highlighted participant education by palliative care professionals as central in building caregiver resilience through the engagement of FCGs in designing, planning, and implementing EOL caregiving strategies. Williams (2018) revealed that the Canadian society must ensure that palliative and end-of-life (EOL) caregivers receive the support they need through adequate caregiving education, training, mentorship, and support services. Participants in this study valued the teachings of palliative care professionals to manage complex needs, linking this formal support to improvement in the EOL experience of in-home caregiving for themselves, their family members, and their loved ones. Ellington et al. (2018) emphasized that the most important

aspect of formal support was the value of expert teaching because it made participants feel confident and supported by detailed instruction and explanations for specific tasks, policies, and procedures. Palliative care professional support for FCGs was the outcome of intentional collaboration, which involved education and mentorship to manage complex needs, a concept crucial for building resilience among immigrant FCGs in this study.

Spirituality

Spirituality was a significant source of comfort and encouragement for participants in this study; many turned to transcendence as a source of strength and resilience during EOL in-home caregiving. The transcendence was an expression of a relationship between participants and their God, encompassing rituals such as praying, meditating and the following of other religious beliefs given by a supreme being. Many studies have included spirituality in the multidimensional definition of resilience (Smith et al., 2012; Richardson, 2002; Walsh, 2003). Participants talked often about the centrality of their faith and religion as a means of coping. Participants who relied on a higher power felt less pressure to control every circumstance of EOL caregiving and frequently had positive appraisals for uncomfortable situations, even in the most desperate ones. According to Baldacchino and Buhagiar (2003), spirituality is crucial in gaining intimacy with family, friends, and others; achieving a life transformation; connecting with the inner self through meditation or contemplation, finding hopefulness in the future; helping others and appreciating nature. In this present study, spirituality was central in the decision to keep a loved one at home and served as a powerful internal resource for participants faced with challenges associated with EOL in-home caregiving. Interview data revealed a strong correlation between spirituality and resilience, as some participants reported using it daily as a guide through the challenges of caregiving, facilitating positive thoughts from adverse circumstances. One participant reported putting everything in “God’s hands” when asked about her father’s travel

plans as a terminally ill patient. Participants discussed the importance of a divine support system in dealing with in-home caregiving adversities and their reliance on spirituality to maintain dignity. Many participants revealed that spirituality is at the core of whom they and their loved ones were as human beings, alluding that spirituality was an intrinsic and essential component of resilience at EOL care. Manning (2013) described spirituality as a means or pathway to resilience that led to subjective well-being. All participants who spoke about spirituality related it to religion and religious practices different from the broader association of spirituality to include more than just religious faith and organized religion. Gunnestad and Thwala (2011) reported that religion could be crucial as a source of resilience, depending on how the religion is taught and utilized. Spirituality emerged as one critical dimension for participants' cognitive, emotional, behavioral, interpersonal, and psychological facets of participants' EOL coping skills. For many participants, it was more than just a moral guidance or belief system; it served as a complement to medical treatment. Their spiritual relationship allows them to remain optimistic during challenging moments and identify God's presence, which allows them to find meaning in their lives (Koenig, 2009). It helped many FCGs make sense of life during the challenging times of EOL, serving as a source of encouragement and highlighting participant's cultural perspectives. Sharma et al. (2017) confirmed a connection between spirituality and resilience and their combined impact on healing, coping, emotional and mental well-being. Through tangible forms (spiritual support groups and items) and intangible forms (faith and beliefs, meditations), participants could cope by finding meaning, gaining control, gaining comfort and closeness to God. Spirituality was unique in building participants' resilience because it was not entirely dependent on physical abilities, unlike many other coping resources.

Practically, spirituality provided support and guidance to participants in complex situations of EOL caregiving – frequently expressed by participants in the form of hope and optimism. In this

present study, remaining hopeful and optimistic was highlighted by participants as a significant coping strategy when they alluded to resilience because of spirituality. Concerning palliative care nursing, Herth (1993) defined hope as “an inner power that facilitates the transcendence of the present situation and enables a reality-based expectation of a brighter tomorrow for self and others” (p. 546). Much of literature views the concept of hope in terms of a cure or remission of disease (Nuland, 1994); however, in the context of EOL caregiving, hope for a cure is lost. Participants viewed hope in this study in terms family context and time factor. Hope in the family context related it to the well-being of themselves (participants), of their loved ones, the larger family unit, while the time factor measured EOL hope in minutes, hours, and days of EOL in-home caregiving. Hope as a source of resilience was facilitated by spirituality, particularly belief systems, whereby the participants were prepared for death of their loved one in both practical and emotional ways. Lai et al. (2018), in their study of spirituality in FCGs suggested that caregivers with higher intrinsic spirituality (personal, intimate spiritual beliefs) spent more time with the terminally ill relative and experienced lower negative feelings and, consequently, fewer emotional distress. This is consistent with the present study results as many participants acknowledged that a relationship with a higher power gave them hope to deal with caregiver burden and the emotions associated with the impending death of a loved one. Ivancovich (2005) suggested that for the individual facing the expected death of a loved one, the recognition of order in the universe due to an omniscient, omnipotent, and omnipresent God may provide enough of a ‘why’ for the individual to engage, even embrace, the suffering as acceptable. Many participants’ spirituality was critical for an optimized EOL in-home caregiving experience, a peaceful death, and the ability to cope after death – further highlighting the importance of hope. Hope became a critical piece of spirituality and a by-product of the EOL religious rituals both for the present caregiving circumstances and the future after death, supporting the idea that hope can be encouraged through solid

spiritual beliefs (Duggleby & Wright, 2005). Gunnarsson and Öhlén (2006) revealed that with impending death, the family's hope starts to focus on other aspects: that the patient dies peacefully or that they feel like they played their role as caregivers well. This highlighted the overall positive effects of hope in this study, as many participants alluded to finding inner strength through spirituality, suggesting a relationship between hope and resilience. Revier et al. (2012) reported that hope fostered a strategy of cognitive re-framing in which participants let go of expectations or the desire for things to be perfect as they established a sense of perspective. The use of hope as a part of building resilience was critical because of the paradox that exists EOL in-home caregiving – the paradox of how to maintain hope while facing the reality that a loved one is dying (Reimer et al., 1991). Nevertheless, participants had to draw on hope as a spiritual resource to help cope with the paradox of EOL and the challenging circumstances that accompany it.

Optimism in EOL in-home Caregiving

Closely related to the concept *hope* in spirituality as a source of caregiver resilience, was the concept of optimism at EOL. In this present study, optimism connected the two sub-categories of spirituality and positive affirmations in EOL caregiving. Matthews and Cook (2009) purported that religious beliefs and personality traits proved to be mediators for the relationship between optimism and well-being. Like *hope*, optimism enabled participants of this study to have a positive anticipatory attitude about EOL in-home caregiving and life after the death of a loved one. Bruininks and Malle (2005) differentiated the two (hope and optimism) by saying people will hope for important things despite a low likelihood of realizing that outcome. In contrast, optimism is more closely attuned to the probability of an outcome occurring. Spirituality and positive affirmations supported participants' use of optimism to prevent self-sabotage and regulate negative emotions associated with caregiving. Luthans et al. (2007) in defining “positive psychological capital” (p.3) as an individual's positive

psychological state of development, used the concepts of optimism, hope, and resiliency as characteristics of positive psychological capital. These characteristics had the potential to cultivate a positive outlook on how participants perceived in-home caregiving challenges. Optimism in EOL in-home caregiving enabled participants in this study not dwell long on negative thoughts of caregiving but instead changed them to something positive and rewarding.

Contador et al. (2012) argued that optimism (the result of positive affirmations) prevents subjective overload of family caregivers, suggesting that participants' positive view served to moderate the negative effect of EOL caregiving. When participants were optimistic, they appeared positive, confident, and persistent in the face of their diverse in-home caregiving challenges. They set attainable goals within their physical and emotional abilities, used family and palliative care support to realize them. Carver et al. (2010) associated optimism to two coping responses: those that are problem-focused (planning, seeking instrumental support) and those that are emotion-focused (cognitive restructuring, acceptance) but both allowed participants to focus on the overcoming physical and emotional aspects of in-home caregiving. In this present study, participants' coping using social and cognitive filters promoted an interpretation of their EOL in-home caregiving experiences in the most favorable and achievable outlook within reasonable limits. Ruisoto et al. (2019) showed optimism as a significant predictor of QOL among informal caregivers after controlling for the effect of different covariates. Even though the present study's data suggested a correlation between optimism and caregiver resilience, it was difficult to understand how they related to each other in in-home caregiving. This was difficult because the study data did not differentiate the two and also it was challenging to determine which of the two preceded the other highlighting the question – is resilience the product of optimism or vice versa? Nonetheless, participant data purported improved caregiver resilience when they remain optimistic about EOL caregiving.

Routines in EOL in-home caregiving

All the participants in this study relied heavily on caregiving routine to guide interactions with informal and formal supports particularly, palliative care professional and other medical appointments. Caregiver routine proved beneficial for the achievement of expectations and outcomes within the confines of in-home caregiving complexities. D'Amen et al. (2021) revealed that caregiving is a dynamic process that involves caregivers, care recipients, and other psychological and relational aspects. The relational aspect of caregiving placed routines as central in coordinating schedules between informal caregivers and palliative care services. According to Spiro (2001), routines were critical for adherence to treatments, evident as participants collaborated with formal services by integrating professional opinions into their loved one's lifestyle, values, and preferences for EOL care. While there is no direct link between building caregiver resilience and adherence to EOL care in the literature, routines made participants and their families efficient in in-home caregiving. It reduced the need to make decisions daily and enabled participants to know exactly what tasks to do without having to contemplate, decide or think too much. With advice from palliative care professionals on such things as medication actions, caregiving times, and appointment times, participants could arrange routines so that culturally relevant activities like meals, meal times, prayer times and family bonding when it was most convenient for the terminally ill loved one. Participants felt that having a pattern of events helped ease in-home caregiving frustration and offered security and comfort to the care recipient. Howe (2002) revealed that family routines were an excellent way to observe how families negotiate competing agendas, especially in accomplishing a task. Routines supported a structure focused on managing interactions with formal services and other family members in a pragmatic and effective way. They became familiar guiding structure to be relied on, particularly with EOL caregiving uncertainties; thus, providing a sense of control. In their study, Spagnola and Fiese (2007) reported that routines are

characterized by communication that is instrumental, involves a momentary time commitment, and are repeated regularly. Participants in this study used routines to organize and prioritize caregiving tasks to guarantee flexibility and rest periods. The predictability and flexibility of routines reduced anxiety associated with in-home caregiving; because participants knew what they were facing and that they could do it. In addition, routines offered consistency that brought comfort, ascertained caregiving action and rituals, promoted a sense of inner peace and alignment – all critical for caregiver resilience.

Positive Affirmations

The last sub-category was positive affirmations, which were used by many participants in this study, and often connected to spirituality and religious practices. However, positive affirmations were not limited to spirituality and religious practices as many participants (even those who did not use spirituality and religious practices) used positive phrases and sacred writings to self-motivate, encourage positive changes in thought processes, or boost self-esteem about EOL in-home caregiving. In this study, it was challenging to differentiate positive affirmation from spirituality and religion sources because they all formed part of the self-concept. The self-concept was integral and composed of different domains which included participants' values, social identities such as racial, cultural, and gender groups; and belief systems, such as religious beliefs among many others. Marsh and O'Mara (2008) reported that the self-concept was not an entity within the person but a hypothetical construct that is potentially useful in explaining and predicting how persons act. The self-concept was important for the outcome of EOL as it was formed from participants' perceptions and interpretation of their in-home caregiving environment. Nonetheless, one critical component of positive affirmation regardless of the source was participants' motivations to maintain a positive self-view about the EOL in-home caregiving competence for themselves and their loved ones. As one participant noted about keeping at loved at home for EOL "it is who we are, it is how we were raised".

All the participants were the primary caregivers with many implying that they were best option for the roles. Participants' confidence was backed by communications with palliative care professionals which were both supportive and empowering in relation to decision making on behalf of their loved one. This view suggested the importance of self-awareness and self-competence, highlighting one key psychological theory behind positive affirmations – self-affirmation theory (Steele, 1988). Self-affirmation is a theory that begins with the premise that people are motivated to maintain the integrity of the self (Steele, 1988). The motivation to protect integrity in caregiving proved to be especially consequential in the context of EOL in-home caregiving. For example, a participant who was often caught up in negative emotions about the nature of her husband's care said "Probably I am not that perfect but for my husband's care? I feel like I do [it] better. So that's why it [caregiving] doesn't make me tired. I like it". She placed herself as an expert in her husband's care, using positive affirmations to combat a potential negative subconscious pattern and replace it with more adaptive outlook on caregiving. Sherman and Cohen (2006) in their study proposed that self-affirmation theory gives a different kind of psychological adaptation – one that, under many circumstances, enables both the restoration of self-integrity and adaptive behavior change. This was exemplified in participants who used positive affirmation mantras to accentuate caregiving competence or in some cases minimize EOL in-home caregiving stress in order to establish a positive outlook. In the course of EOL in-home caregiving, there were potential events that could threaten participants' self-integrity and adaptive adequacy such as worsening condition of a loved one – affecting their sense of success and their ability to control EOL caregiving outcomes. These events shaped EOL caregiving outcomes and prepared participants to overcome caregiving challenges. Cohen and Sherman (2014) identified three points of emphasis with the theories of self-affirmations needed for overcoming negative views of an event (s) and maintain self-integrity in this case EOL in-home caregiving. First, the motive is to maintain a

global narrative of oneself as a moral and adaptive actor (“I am my husband’s primary caregiver”). Here participants may commit themselves to a particular self-definition (EOL caregiver) with a variety of roles and identities to maintain perceived integrity and guarantee flexibility. The flexibility of the self-system was critical because it can promote adaptation, especially in dynamic social systems (Cohen & Sherman, 2014) such as EOL in-home caregiving. Second, the motive for self-integrity is not to be superior or excellent, but to be “good enough,” as the term “adequate” implies (“I am the best person for my husband’s care”) – to be competent enough at EOL in-home caregiving. Here, participants had a good sense of adequacy in a personally valued domain of EOL in-home caregiving and not a perception of overall excellence. Third, the motive for self-integrity is not to esteem or praise oneself but rather to act in ways worthy of esteem or praise. Here participants did not seek praise or admiration but rather perform EOL caregiving abilities because they are meaningful, thoughtful, and necessary to maintain the dignity in dying for loved ones (I do it because it is the right thing to do). In this study, these motives of self-affirmation were applied in varying degrees and at different times by participants as methods to maintain focus on the goals of EOL caregiving and as stress management. Participants’ positive affirmations supported an integral view of self and available internal resources needed to support EOL in-home caregiving with a positive outlook. Positive affirmations reassured participants of their value and integrity with respect to caregiving of their loved one, providing balance in spite the adversities before them. Even though these ideas may be common among immigrant FCGs and the Canadian born FCG, the differences become accentuated when a cultural lens is applied. Nonetheless, there are major overlaps between these two groups when it comes to caring for a loved one at home, highlighting the influence of acculturation in EOL in-home caregiving. This is particularly true for immigrant FCGs who have been living in Canada for a while and have adapted the Canadian way of life about death and dying.

Strengths and Limitations

In reflecting on the strengths and weaknesses of the study, the student researcher explored the various aspects of the study and critiqued them. The strength of this study is the value it places on the lived experience of immigrant FCGs (a significant part of the Alberta population) in caring for a loved one nearing the end-of-life at home. The findings of this study also have the potential to improve outcomes for immigrant FCGs and their loved ones, considering the significant social and cultural influences they have on in-home caregiving. Another strength of this study is that it applied a Constructivist Grounded Theory (CGT) lens to explore the co-constructed meanings of immigrant family in-home caregiving. This highlighted the significant role the student researcher played in developing this theory. The co-construction of data in constructivist version of grounded theory alerts researchers to their role in shaping the data (Charmaz, 2014). However, the theory that emerged is open to varying interpretations.

Conversely, this current study is not without limitations. The main limitation of the study methods was the inability of the results to be generalized to a larger population for several reasons, this is unsurprising to qualitative studies. First, I achieved data saturation after completing seven interviews which could be considered a small sample size. The small group of participants in this constructivist grounded theory study may limit its transferability. The goal of a qualitative research is to offer unique opportunities for understanding complex, nuanced situations where interpersonal ambiguity and multiple interpretations exist (Austin & Sutton, 2014). Despite the inability of qualitative research to provide definitive answers to complex issues such as EOL in-home caregiving for immigrant FCGs, it can yield a better understanding and a springboard for further focused work in this area. Secondly, the use of a purposive sampling in this qualitative study limits its generalizability to the larger population of immigrant FCGs. Thirdly, the study had participants with varying religion and religious rituals,

further limiting the transferability and generalizability of the findings. Spirituality has different meanings and roles in different cultures, countries, religious confessions. Furthermore, the participants were from diverse cultural backgrounds and residing in one city in Alberta, meaning the research data may not apply to people in rural communities. Additionally, anecdotal evidence suggests that PHC and PCSS HCPs only approached patient/immigrant caregiver dyads who were willing to share their stories, possibly using some form of a biased judgment. Also, the individual participant's ability to recall in-home caregiving events, emotions, interview method, and how busy they are may have affected outcomes. Similar factors may also influence CGT interviewing and my perception of what is being communicated. Also, considering this was my first research study, I struggled with CGT interviewing. Hence, I was learning through the process, in collaboration with my supervisor.

Implications for Nursing

The purpose of this study was to generate a theory that will explain the experiences of immigrant FCGs supporting a dying loved one at home. The emergent theory of *An Immigrant family caregiver experience of EOL in-home caregiving: A Relational Process of Maintaining Dignity in Dying* presents a fresh outlook on how individuals maintain the dignity of their loved one while providing informal caregiving. In particular, the findings from this study highlight the uniqueness of participants and their in-home caregiving situations. Exploring this uniqueness has revealed the importance of cultural norms and practices, family unit, and caregiver resilience in having an optimal experience of EOL caregiving and adoption of palliative care services with implications for future research and nursing practice. The concept of maintaining dignity and its application becomes central in the emergent theory.

Implications for Nursing Research.

This study is one of the few known research projects that examined the immigrant FCG experience of in-home caregiving in Alberta. Findings from this study revealed the need to recognize the unique cultural identities and expectations that diverse immigrant populations possess in order to appreciate how different they are from Canadian born FCGs. After exploring the narratives of each participant and engaging in data analysis, it has opened an opportunity for future research. First, given the limited research in the immigrant family in-home caregiving during EOL, more qualitative research is needed to peel away the complex layers of the influence of immigration status and culture identities on EOL in-home caregiving. Second, because this study identifies the immigrant FCG experience of in-home caregiving as unique and pivotal in maintaining the dignity of a dying relative, future research could focus on how palliative care services adapt to serve diverse immigrant populations better. I would also suggest researching the interplay of acculturation on immigrant FCGs' perception of palliative care services and EOL in-home caregiving; the heterogeneity of caregiver resilience among immigrant FCGs for EOL in-home caregiving just to name a few. Other directions for future research may involve exploring inter-cultural differences in how immigrant FCGs experience in-home caregiving in Alberta.

Implications for Nursing Practice

This study's findings have direct implications for nursing practice. First, it will support educative programs for immigrant family caregivers about available formal services. Reaching out to culturally diverse groups might help create awareness on what is available to support EOL caregiving. For instance, palliative care nurse educators could design educational seminars offered to immigrant FCGs in their language at various cultural organizations in the community where immigrants may frequent. Thus, an understanding of defined roles, barriers, and benefits of a particular culture about EOL in-home caregiving can be addressed. Second, this study might be helpful in the protection and promotion of resilience among immigrant FCGs, a priority for mental health nursing. The promotion of resilience

is important because it involves responding to the challenges that affect the immigrant FCG's ability to use coping skills effectively with the challenges of EOL in-home caregiving. Through this, caregivers may be presented with additional opportunities to share information and insights about caregiving within a cultural context. Nurses in palliative care units and community departments can advocate for EOL in-home caregiving services that reflect immigrant preferences and expectations. This study can suggest to palliative care stakeholders, creative ways to support EOL in-home caregiving for diverse populations in a culturally sensitive way. Finally, it might be beneficial to have a support group of immigrant family caregivers. This might help provide ongoing support where FCGs can meet other caregivers and share their stories.

The theoretical model presented in this study has important implications for the education of all medical professionals working with diverse groups of patients and their FCGs. With a growing visible minority, palliative care services from Albertans born in another country will grow higher.

Policymakers are in a unique position to improve palliative care access – I believe this involves targeting diverse immigrant groups and fostering an environment that seeks to improve the use of palliative care services through public awareness. Another suggestion would be to educate nurses on the cultural expectations of different diverse groups, how they perceive death and dying, and how they intend to foster dignity in dying for both the FCGs and their loved ones.

Perhaps sensitive cultural training in nursing education should consider the immigration history of patients and their FCGs on how to integrate sensitive and considerate strategies and not rely on the standardized biomedical approach to EOL care that seems to be deeply rooted in Western society. This theory can help palliative care HCPs to understand the value of cultural norms and values, caregiving as a family unit, and the need to build caregiver resilience among immigrant populations.

Consequently, palliative care HCPs can be prepared to provide an individualized care approach to the

immigrant FCGs and their loved ones at EOL. The findings from this study also highlight the experience that each FCG has with cultural expectations of EOL caregiving and death.

According to Anderson et al. (2003), a health care workforce equipped in cultural competency and awareness has a positive contribution towards the elimination of health disparities. An immigrant's cultural upbringing may impact a patient's level of engagement in care planning, their choice of treatment, and adherence to treatment. A patient's culture can also affect their interpretation of symptoms, coping skills, and overall approach to health, thus cultural consideration becomes significant.

Implications for Health Systems

This study's findings can be beneficial for the inclusion of a Family Centered Care (FCC) approach to EOL in-home caregiving by the health system. Palliative care professionals can support family involvement for the provision of physical and emotional healing, optimal well-being, and the sustainability of a quality EOL. The health system can create clinical guidelines to help nurses and other disciplines assimilate and implement knowledge on FCC in relation to in-home caregiving. Through this, the interdisciplinary team could advocate for FCC policies within the organizational structure particularly during decision making. FCC approach will contribute to a culturally sensitive care plan, support palliative care's discussions about relevant cultural needs, as well as immigrant FCGs' strengths and weaknesses related to personal values, preferences, and ideas. Caregivers' and their loved ones' social, religious, and cultural backgrounds can influence the provision of care to their family member.

Conclusion

Using the CGT methodology, a substantive theory has emerged that attempts to explain the experiences of immigrant FCGs with EOL in-home caregiving. The theory, *Immigrant family caregiver*

experience of EOL in-home caregiving: A Relational Process of Maintaining Dignity in Dying, attempts to explain the experiences of supporting a loved one at home for EOL as an immigrant FCG. The theoretical model presented in this study can assist palliative care HCPs to be in a better position to support, empower, and encourage immigrant FCGs throughout the EOL in-home caregiving. Within this theoretical model, it is evident that immigrant FCGs are involved in maintaining the dignity of their loved one by keeping them at home for EOL care. The sample of this study was too small to be able to identify if there were novel or unique findings for immigrant family caregivers as opposed to Canadian born FCGs in relation to EOL in-home caregiving. However, it seemed evident in this research study that the connection participants felt to their country of origin, their culture of origin and the idea of who they were pre-immigration remained influential on how they perceived and experienced EOL in-home caregiving. This connection or the lack thereof coupled with immigrant FCGs' acculturation in Canada made participants' experiences of EOL in-home caregiving worthwhile. It made participants uphold in-home caregiving as ideal for EOL experiences based on what is culturally valuable at this point in time. This study also showed that some participants were unaware of the extent of services that palliative care services offer begging the question of how much awareness is expected from an immigrant FCG new to EOL in-home caregiving. At the same time, there may be many reasons for this gap in knowledge by immigrant FCGs. Perhaps the findings in this study highlight the need to create awareness among this population and implement an individualized EOL care approach to health and well-being. This was corroborated by the literature review which explored the complexities of culture, immigration, the home, EOL caregiver resilience, connection and the factors that impact the experience of in-home caregiving by participants. Throughout the literature review, it became evident that these attributes were both blessings and curses for the participants and no single factor is responsible for maintaining dignity of a dying loved one.

The purpose of this research study was to answer the research question, *What are the EOL in-home caregiving experiences of immigrant family caregivers?* Exploring the experiences of immigrant FCGs who had or still are supporting a dying loved one at home has shed light on this complex question. The findings in this study suggest that the primary reason for in-home caregiving by this population is to meet cultural and personal caregiving expectations for their loved ones. The realization that the expectation and experience of EOL in-home caregiving were shaped by multiple factors was highlighted by participants' unique circumstances. The key to understanding immigrant FCGs and their loved ones is acknowledging the role their cultural differences and circumstances play in EOL in-home caregiving. After acknowledging a terminal illness, participants must move through the phases in the core process in this study; it is evident that decisions are focused on maintaining dignity in the dying of a loved one. This approach supports a holistic view of EOL in-home caregiving which is attuned to the W.H.O.'s definition of palliative care.

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Appendix A-Consent Form**STANDARD CONSENT FORM**

TITLE: The Experience of Palliative Home Care by Immigrant Family caregivers in Alberta

SPONSOR: University of Calgary

INVESTIGATORS: Dr. Shelley Raffin Bouchal

+1(403) 220 6258

Rhodric Gana

+1(403) 390 5745

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

BACKGROUND

Many Canadian patients want to remain at home even when support is limited (Canadian

Institute for Health Information [CIHI], 2011). The growth in demand for home-based care has prompted a trend towards palliative care delivered in the home as well (Guerriere, Zagorski, Fassbender, Masucci, Librach, & Coyte, 2010; Romanow, 2002). While home-based palliative care is associated with higher levels of patient and Family Caregiver (FCG) satisfaction (Dhiliwal & Muckaden, 2015), many FCGs who assume this role become vulnerable to personal economic hardship and financial stress, as well as fallout from such stress in the form of poorer health (National Alliance for Caregiving & Evercare, 2009; National Family Caregiving Association, 2009). This is no different for immigrants who are unfamiliar with the health care system. In fact, it can be potentially worst for immigrant family caregivers considering the barriers they already face with integration and adaptation. This background supports my research focus which is to uncover the process of how immigrant family caregivers navigate Palliative Home Care (PHC) in Alberta. This research has implications for Health Care Providers' (HCPs) understanding and support for immigrant FCGs. Results also present a platform for future research in immigrant health and support systems.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this qualitative study is to understand the process of how immigrant FCGs navigate regular Palliative Home Care (PHC) services in Alberta. This study will explore how the immigration status FCGs influence the navigation of PHC when supporting a dying relative.

WHAT WOULD I HAVE TO DO?

You will be asked to participate in a one to one interview to discuss your experience as an immigrant navigating the PHC system as you support your relative. This interview will be recorded and transcribed (typed word for word) for analysis with the possibility of a follow up phone call for any possible clarifications. You do not have to answer any question if you do not want to.

WHAT ARE THE RISKS?

There are no foreseeable risks. If the discussion of your experiences triggers any negative thoughts in you, the interviewer will stop this interview and provide contact information for counsellors of the existing PHC program. There are no direct benefits either, although it is hope that you will find the interview an enjoyable experience.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. However, information gained from this study may help us better support immigrant family caregivers who are navigating an unfamiliar health care system especially PHC

DO I HAVE TO PARTICIPATE?

Participation in the study is voluntary and you may choose to withdraw from the study at any time without jeopardizing your health. If you choose to withdraw, please contact the Principal Investigator Dr. Shelley Raffin Bouchal for withdrawal. Once the student investigator has reached a certain point of this research -one on one interview, it may be impossible to withdraw the information received from you..

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Aside from the 60- minute interview, there is a possibility the researcher will do a follow up phone call for clarifications of data if necessary.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your involvement and neither will you pay anything

WILL MY RECORDS BE KEPT PRIVATE?

The records of the interview will be downloaded and stored in a password protected computer of the student. Records will be transcribed and transcripts will be kept private in a locked cabinet in the office of the primary investigator. Only those directly involved with the research will have access the digital recordings and to transcripts and recordings. Further, we will ensure that only pseudonyms are used, all names and identifiers will be removed from transcripts. Consent forms, transcripts and all notes will be shredded after 5 years as per University of Calgary policy. Audiotape memory and password encrypted stick will be deleted once data collection is complete

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Shelley Raffin Bouchal (403) 220-6258

Or

Rhodric Gana (403) 390-5745

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

<hr/>	
Participant's Name	S
<hr/>	
Signature and Date	
<hr/>	
Investigator/Delegate's Name	
<hr/>	
Signature and Date	
<hr/>	
Witness' Name	S
<hr/>	
Signature and Date	
<hr/>	

Appendix B- Participant Interview Guide

Prompts for interviews with key informants

- 1) Please tell me about your experiences caring for your family member at home?
- 2) Tell me about your experience with how you made the decision to take care of your family member at home? Please tell me about a typical day when you first started taking care of your family member at home. How about later on?
- 3) What is your experience with the Canadian Health care system?
- 4) Tell me about your experience in with health care providers around your family member's care needs? How about your own needs related to the care of your family members?
- 5) Overall, what are your experiences with Palliative Home care?
- 5) How have you been able to access available services/departments for the patient? How do you request for PHC services?
- 7) How has caregiving affected you? Did you have to make any changes because of PHC services? In your house, routines, family ties?
- 8) What are the Challenges you have experienced with PHC?
- 9) What have been the benefits of PHC?
- 10) Is there anything else that you would like to tell me that I have not asked you?

Appendix C-Family Caregiver Demographic Form

1. Birthdate: Year _____

2. Sex Male Female Other (Please specify) 3. Living situation
(check all that apply)

Alone

Spouse/partner

Child(ren) under 18, if yes, number of children under 18: _____

Other adult(s), if yes, number of other adults: _____

Common law (Spouse de facto)

Divorced/separated

Married

Single

Widow Other, specify _____

4. Language(s) spoken

English

French

Mandarin

Cantonese

Tagalog

Arabic Other(s), please specify: _____

5. Where were you born? _____

6. What is the year of your arrival/immigration to Canada? _____

7. Education

(highest level of education completed)

< High school Completed high school Some post secondary education College
 diploma Bachelor's Degree Master's degree Doctorate

8. Current employment status:

Full-time Part-time Casual Unemployed Disabled Homemaker Retired
 Sick leave Compassionate Care Leave Other _____ If

currently employed, list occupation: _____

If you are not currently employed, list previous occupation: _____

9. For Care recipients and caregivers, types of health care resources:

Family physician

Specialist, if yes list:

Other, if yes list: _____

Appendix D- Participant Characteristics

Interview	Participant Pseudonym	Age	Years of informal Caregiving	Country of Origin	Year of immigration	Caregiving recipient
1	Melissa	62	23	Iran	1983	Mother-in-law
2	Jasmin	32	10	India	1995	Grandmother
3	Glory	35	10	India	2005	Mother
4	Nasa	69	12	India	2001	Mother-in-law
5	Camille	61	15	Philippines	1991	Husband
6	Stella	59	4	Ukraine	2006	Father
7	Amanda	51	12	Philippines	1993	Father

Appendix E- Coding Table

Overarching Theory Immigrant FCG experience of EOL in-home caregiving: A relational Process of Maintaining dignity in dying.		
Initial Codes	Focused Codes	Theoretical Codes
Cultural Rituals FCG values Home at all costs Faith/Spirituality	Cultural Values	Cultural Values and Norms of Caregiving
Rallying informal Support Coordinating Care Presence	Family Caregiver Reciprocity	Caregiving as a Family Unit:
Awareness of upcoming challenges Increasing family support Adaptation, Routines/schedules, Organizing, Structural and logistical changes to housing	Preparedness	Building Caregiver Resilience
Monitoring loved ones' needs Assessing Caregiving progress Learning and seeking education from Palliative care HCPs to manage complex needs Overcoming Challenges	Resilience	