

FOSTERING FAMILY RELATIONSHIPS IN LONG-TERM CARE

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Abstract

Family relationships are a significant part of a person's life. Unfortunately, moving a relative from a family home into a long-term care (LTC) home requires the readjustment of family relationships from a familiar to a foreign environment and puts these relationships and associated family identity at risk. With the shift in focus to person-centred care and its need for the maintenance of family connection, the fostering of family relationships in LTC homes becomes an important part of properly enacting this approach to care.

This critical ethnography explored the ways in which family relationships are fostered in LTC and identified the efforts made and barriers that exist in the broader organizational and social context of LTC that influence how these relationships are fostered. Data from a larger critical ethnography was collected through semi-structured interviews with and participant observation of 12 family members, seven staff members, and three residents from a LTC home in an urban city in British Columbia, Canada.

Family members came into the LTC home to spend time with their relative and maintain a connection with them, but a lack of opportunity to take part in activities that recognized the importance of these connections prevented family relationships from being fostered. Task-focused care overlooked the importance of relational care and further prevented family relationships from being maintained. Physical and cognitive decline also made it difficult for family members to engage and connect with their relative, resulting in a significant impact on the fostering of family relationships. Driving distances and a lack of opportunity to maintain connections with relatives outside of the LTC home added to the challenge of fostering family relationships. Family members want to maintain family identities and associated relationships

but require support in doing so. The findings from this study have implications for nursing practice, administration, education, and research.

Lay Summary

Family relationships are an important part of a person's life and are necessary for maintaining dignity, identity, and connection. Unfortunately, moving into a long-term care (LTC) home puts these relationships at risk. This research study aims to understand how family relationships are fostered in LTC during a relative's time of ill health and cognitive decline. Suggestions for policy, education, and nursing practice are presented with the goal of improving the quality of resident care and the ways in which family relationships are fostered in LTC.

Preface

This thesis is unpublished, original, and independently written by the author, J. McDougall. The ethics certificate number for the IDEAL study that this study used data from is H13-01800.

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CHAPTER 1: PROBLEM IDENTIFICATION AND PURPOSE

1.1 Introduction

Family members of long-term care (LTC) residents describe moving their relative into a LTC home as one of the most difficult times in their life (Holmgren, Emami, Eriksson, & Eriksson, 2013; Moore & Dow, 2015). Family members and residents experience a sense of loss for previous relationships following such a move (Bramble, Moyle, & McAllister, 2009; Lloyd, 2010; Reuss, Dupuis, & Whitfield, 2005) and identify the transition from home into LTC as more than simply a change in location (Abrahamson, Sutor, & Pilleme, 2009). For many family members, maintenance of relationships with their relatives becomes an important adaptation to help them cope (Bauer, 2006) and provides continuity of routine from home into LTC. For residents, facilitating family relationships recognizes and celebrates their continuing place in community and enhances their personhood (McCormack, Roberts, Meyer, Morgan, & Boscart, 2012). The unfamiliarity of a new care setting and its associated routines, the introduction of new care givers, and the loss of previous identities (Eika, Espnes, Söderhamn, & Hvalvik, 2014; Lloyd, 2010) act as barriers to maintaining past relationships. Despite organizational goals of person and relationship-centred care that put residents and their family members at the center of care, differences between the care provided at home and in LTC exist and result in the latter having less focus on the maintenance of family relationships (Moore & Dow, 2015). There is a concern on the part of family members that their relative will not be understood, known, and loved by staff¹ after placement (Austin et al., 2009), highlighting the importance that family members place on existing relationships as a means to preserving the self-worth, personal

¹ Throughout this paper, the term *staff* refers to care-aides, registered nurses, and licensed practical nurses unless otherwise specified.

identity, and dignity of both residents and family. The preservation of the previously mentioned characteristics contributes to the enhancement of person-centred care in LTC.

The focus on person-centred care in LTC (Siegel et al., 2012) has signaled a shift in philosophy from a model of care that emphasizes illness, disability and dependency and primacy of institutional norms and routines to one that is responsive to the needs of residents (McCormack et al., 2012). An important part of person-centred care includes the facilitation of relationships that enhance the personhood of residents and others significant to them (McCormack et al., 2012). Therefore, the ways that residents and their family members engage in relationships influence both the extent to which they are seen as persons and the degree to which person-centred care is enacted (McCormack et al., 2012). Despite the sociocultural, political, professional, and organizational contexts found in LTC and the countless interrelated aspects of these contexts that facilitate or hinder the capacity to carry out this type of care (Siegel et al., 2012), family inclusion and the nurturing of family relationships remain key elements of person-centred care (Alzheimer Society of Canada, 2011; Crandall, White, Schuldheis, & Talerico, 2007; McGilton et al., 2012)

Along with a philosophical shift towards person-centred care, new residents moving into LTC are increasingly medically and socially complex, resulting in time constraints and increased workloads that limit the ability of staff to be attentive to the value that family members and residents place on existing family relationships (Austin et al., 2009). Confusion around LTC homes serving as both a healthcare setting and a home also takes away from a needed focus on family relationships (Habjanič, Saarnio, Elo, Turk, & Isola, 2012). In addition to increasing workloads, task-oriented approaches to care often take priority over person-centred care (Bauer,

2006; Brown-Wilson & Davies, 2009) and deflect the time and attention required to help support maintaining family relationships.

LTC homes are challenged by inadequate funding and staffing levels due to a decreasing amount of healthcare spending in LTC (Armstrong, P., Armstrong, H., & Daly, 2012; Cammer et al., 2014; McGilton & Boscart, 2007). The limited resources in LTC contribute to a devaluing of the relationships between family members and residents and continue to prioritize the physical tasks of care (Bauer, 2006). It is important that the context that shapes the acts of care in LTC not be overlooked (Baumbusch & Phinney, 2014; Cammer et al., 2014; Siegel et al., 2012).

An examination of the influence of the broader organizational and social contexts of LTC can help to explain how families situate themselves, how they are situated by staff working in LTC, and the extent and the ways in which family relationships are fostered (Baumbusch & Phinney, 2014). A lack of organizational policies that address family involvement and provide direction for their role has resulted in conflicting ideas about the amount and type of attention that should be given to family members and their associated relationships (Baumbusch & Phinney, 2014). The 'First Available Bed' policy, which requires those in need of LTC to accept the first bed that is available and appropriate, also challenges the fostering of family relationships as this policy often results in residents being placed in a LTC home that is geographically at a distance from their families and communities (Baumbusch & Phinney, 2014).

Considering that the preservation of self is a significant part of person-centred care and that our selves are, to a great extent, socially constructed, it is important that the social context of LTC also be examined when looking to maintain self (Ramanathan-Abbott, 1994; Surr, 2006). Relationships with family and the maintenance of family roles are important for the preservations of self, with studies finding the family role to be particularly significant for people

with dementia and those caring for them (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Surr, 2006). These roles, including those of spouse and parent, are co-constructed and therefore require the cooperation of others and a facilitative social context that encourages the continuation of family roles and strengthens sense of self (Basting, 2003; Ramanathan-Abbott, 1994; Surr, 2006). The dynamics that develop from these organizational and social contexts ultimately shape the care and attention given to residents and their family members and help to explain the admission by staff in LTC that only a small amount of their time is put towards building relationships (Bedin, Droz-Mendelzweig, & Chappuis, 2013).

1.2 Significance

Admission of a family member to a LTC home should not signal the start to the end of family relationships. Family members visit and continue to play a role in care in order to show commitment to their relatives in LTC and to maintain, as much as possible, an ongoing relationship (Russell & Foreman, 2002). With the projected increase in the aging population, associated prevalence of dementia, and the expected 10-fold increase in demand for LTC, all aspects of the LTC sector become an important focus (Dudgeon, 2010), including that of fostering family relationships. Many studies have explored the continuing caregiving role that family members play and the extent of their involvement after their relative moves into LTC (Baumbusch & Phinney, 2014; Bramble et al., 2009; Gladstone, Dupuis, & Wexler, 2006; Reuss et al., 2005), and other studies have looked at the relationship between family members and staff in LTC (Abrahamson et al., 2009; Austin et al., 2009). There are studies that have looked at the relationships between residents and staff (McGilton & Boscart, 2007; Nakrem, Vinsnes, & Seim, 2011), but there are a lack of studies that explore how family relationships are fostered in LTC, both actively and passively, by residents, family members and staff alike. There are studies that

draw attention to the importance of sustaining family relationships (Brown-Wilson & Davies, 2009; Ryan & McKenna, 2015), but there is a gap in the literature about the mechanisms (both active and passive) by which these relationships are fostered.

In this study, the fostering of family relationships refers to the efforts made to acknowledge the family roles that residents and their family members continue to play following a move into LTC and the actions taken to allow these roles and identities to persist. Residents are still spouses, parents, siblings, and friends to their family members, and a move into LTC does not rid them of these identities. The aim of fostering family relationships in LTC is to acknowledge and support the connections between residents and their family members. Personhood is based on relationships with others (Penrod et al., 2007), including those with family, and recognition of family relationships aligns with the growing awareness in geriatrics of the importance of considering the social context as a means to providing meaningful care (Clark, 2002). An awareness of the significance of these relationships is needed in organizations and among those that care for residents in LTC (Ericsson, Kjellström, & Hellström, 2013).

In a service system that is task-focused, the socio-emotional aspects of care are often neglected (Brown-Wilson & Davies, 2009; Moore & Dow, 2015), and the importance of the relationships between residents and their family members often go unnoticed (Sandberg, Lundh, & Nolan, 2001). Challenges with maintaining family relationships can therefore result from person-centred care being secondary to task-oriented care (Brown-Wilson & Davies, 2009). This goes against the main LTC objective of making each resident's quality of life as good as possible even with dependency, health problems, and a reduced level of functioning (Bergland & Kirkevold, 2006). Despite these challenges, continued efforts to maintain relationships between residents and their family members allow for a (re)construction and continuation of their life

story and promote a sense of continuity between a resident's past and current situation (Bedin et al., 2013). These efforts support resident's self-determination and uniqueness as well as that of their family members (Bedin et al., 2013).

The cognitive decline and ill health of residents already threaten existing relationships making it imperative that LTC homes create an environment that fosters family relationships. Despite the need for this type of environment, there are challenges to creating an environment that welcomes all efforts to foster family relationships; primarily because of the provision of physical care outweighing family needs and the emotional and social aspects of care (Bauer, 2009; Brown-Wilson & Davies, 2009; Moore & Dow, 2015; Westin et al., 2009). The aim of this thesis project is to improve our understanding of how relationships are fostered between family members and residents in LTC in order to generate recommendations for policies and practices to support these relationships.

1.3 Problem Statement and Study Purpose

In summary, it is evident that our overall understanding of the ways in which relationships between family members and residents living in LTC are supported is limited. Increasing our understanding of how family members, residents, and staff foster family relationships during a time of ill health and cognitive decline is of importance for shaping the attitudes and nursing practices found in LTC homes. The purpose of this study is to gain a better understanding of how family relationships are fostered in LTC within the broader organizational and social contexts in order to guide future policy, education, and nursing practice aimed at improving the quality of resident care.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter provides a review and synthesis of current and relevant literature that supports the context of this research study. It includes a synthesis of literature on the ways in which family members are involved in care, the attitudes that family members, residents, and staff in LTC have towards maintaining family relationships, and the factors that influence the attitudes and efforts towards fostering these relationships. Gaps in knowledge that led to the research questions in this study are also identified.

2.1.1 *Inclusion Criteria for Selection of Studies*

Both qualitative and quantitative studies were included in the literature review. Peer-reviewed, full-text, English-only studies dating back to 2000 were specified in the search criteria. The inclusion criteria did not eliminate any country where a study may have taken place. Participants in the studies included spouses, children, siblings, and friends of residents living in LTC to reflect the varied nature of family. Residents living in and staff working in LTC were also participants in the studies included in the literature review. Only studies that took place in LTC homes were included.

2.1.2 *Identification of Studies*

CINAHL, PubMed, and Web of Science were the databases used to identify the studies used in this literature review. MESH terms used to conduct the search in PubMed included “residential facilities” and “family relations.” Search terms used in CINAHL and Web of Science included long-term care, residential care, nursing home, family relation, and visit. These search terms were used in combination with Boolean operators and truncation.

2.2 Review of Current Evidence

In this section I review the factors that influence the extent to which family relationships are fostered after moving a resident into LTC. These factors include role confusion, continued desire to remain involved, staff influence, and competing demands.

2.2.1 Role Confusion

Family members often experience role confusion after moving a relative into LTC as they adjust to the routines and expectations of a new care setting. Families are often ill-prepared for the institutionalization of their family member and are likely in need of support following admission (Bramble et al., 2009; Keefe & Fancey, 2000; Ross, Carswell, & Dalziel, 2001). Wright (2002) conducted a qualitative study about the roles of family members of residents in LTC and interviewed 61 family members that included spouses and children from 35 LTC homes. The author found that despite the importance placed on family relationships, families are provided with little guidance concerning their explicit caregiving role. An explorative descriptive qualitative study by Hertzberg, Ekman, and Axelsson (2003) that looked at nurses' views and experiences with family members and included interviews with 19 nurses working in LTC found that although staff in LTC may encourage family participation, there is often no support for their involvement. Gladstone et al. (2006) conducted a qualitative study using a naturalistic methodological approach to examine changes in family involvement following a relative's move into LTC as well as the factors associated with these changes. The authors of this study interviewed 35 family members and found that commitment and support from family members with residents in LTC were not influenced by physical and cognitive decline or the fact that their family member lived in a LTC home. Reid, Chappell, and Gish (2007) conducted a quantitative study that assessed family perceived involvement and the importance that family

members place on their involvement in individualized care by analyzing questionnaires completed by 68 family members with a relative in LTC and found that family members will choose to remain involved in the care of residents if the staff and the policies within each LTC home actively engage family to do so.

While family engagement should therefore be encouraged, it should also be voluntary. With increasing resident complexity and a fiscal crisis in LTC, family members are increasingly expected to share the responsibility for caregiving (Ross et al., 2001). This sharing of the caregiving role, if involuntary or unclear, can result in dissatisfaction with the institutional care, feelings of sadness and guilt, and role confusion within the home (Bauer, 2006; Maas et al., 2004; Ross et al., 2001). Ross et al. (2001) conducted a descriptive exploratory study using 122 questionnaires that were completed by family members and gathered data about the patterns of visiting, assistance provided during visiting, and satisfaction with the quality of care. The authors of this study found that uncertainty about family members' roles within the home can leave families unsure about how to make best use of their time and energy while visiting, suggesting that visiting a family member in LTC may not be enjoyable.

There is wide variation in family relationships, reasons for visiting, and family expectations of the care provided, adding complexity to the visiting experience and uncertainty as to how LTC homes can best accommodate visiting family members. In addition, staff in LTC homes often have preconceived notions as to how family members should be involved (Hertzberg et al., 2003). A study by Ross et al. (2001) found that the majority of family members did not enjoy visiting residents in LTC despite this majority still visiting frequently. The same study found that visiting can be a difficult and demoralizing experience and suggested that LTC homes familiarize families with the routines and practices of the home and develop

policies and programs that make the visiting experience as comfortable and meaningful as possible for families and residents. Keefe and Fancey (2000) conducted a study that explored changes in caregiving relationships after a family member moved into a LTC home by quantitatively and qualitatively analyzing in-depth interviews with 214 family members and found that family members want to engage in activities and tasks that provide them with purpose. They also found that the types of activities that families involved themselves in depended on the cognitive ability of their family member and that their involvement often included other residents. When family members felt a lack of anything to do during their visits, they were less likely to stay involved (Keefe & Fancey, 2000).

2.2.2 Continued Desire to Remain Involved

Family members want to be included in caring for their relative after a move into a LTC home and remained involved in several ways. Reasons for visiting vary but most often include checking the quality of care, providing companionship to a resident in care, handling finances, providing practical help, and assisting with personal care (Keefe & Fancey, 2000; Russell & Foreman, 2002; Wright, 2002). The roles that family members choose to take and are expected to take in LTC have raised significant questions regarding the disempowerment of family members and residents in LTC (Wright, 2002). For many, placing a family member into LTC is seen as a last resort after other options have been tried and after families have endured caregiver burnout (Almberg, Grafstrom, Krichbaum, & Winblad, 2000; Keefe & Fancey, 2000). Despite frequent burnout, families did not want to let go of control of their family member's well-being and felt obliged to remain involved in care after placement into a LTC home (Bramble et al., 2009; Eika et al., 2014; Mamier & Winslow, 2014). Even with this desire to remain involved, family members have found themselves taking on a secondary caregiving role and learning to

trust others to make decisions that they once made themselves (Almberg et al., 2000). Although family members could not provide all of the care, they did not want to be replaced by staff (Bramble et al., 2009; Reuss et al., 2005; Sussman & Dupuis, 2012). When staff did not perceive the need for families to remain involved and were not encouraging of their participation, family members felt an added sense of isolation and role confusion, especially around sustaining family relationships (Bramble et al., 2009; Eika et al., 2014). Russell and Foreman (2002) conducted a case study examination that looked at the perceptions and expectations of family members, staff, and residents concerning the role of the visiting family member in LTC using focus groups, interviews, and surveys with 23 family members, 15 staff, three management staff, and six residents and found that for many families, visiting their family member in LTC was an unfamiliar way in which to continue a relationship.

The family member's role associated with caring does not end with placement, nor does their life-long commitment to their family member in care (Bramble et al., 2009; Westin et al., 2009). LTC staff need to "think beyond the person as an individual" and involve family members in activities that contribute to sustaining family identity (Phinney, Dahlke, & Purves, 2013, p. 369). M. Nolan, Davies, Brown, Keady, and Nolan (2003) argue that a relationship-centred approach might be more appropriate and useful than a person-centred approach and highlight the need to value interdependence so that all participants of a healthcare team are meaningfully involved, including family members. They explain that the interactions between residents, their families, and staff make up the defining force in healthcare as they increase our understanding of what illness means through the exchanging of information. Strang, Koop, Dupuis-Blanchard, Nordstrom, and Thompson (2006) conducted an exploratory descriptive qualitative study about the experiences of family members waiting to place a relative into LTC

and the methods of coping during the wait and move into a LTC home using 29 pre-placement interviews and 15 post-placement interviews with family members. They found that a role in care allows for the continuity of past relationships and responsibilities, both of which family members want to maintain. Once families have been relieved of their responsibility to meet the basic needs of their relative at home, they have an opportunity to devote more time to their relationship and the quality of life of their family member following placement into LTC (Bauer, 2006; Gaugler, Anderson, Zarit, & Pearlin, 2004; Maas et al., 2004). Despite there being relief from the day-to-day tasks of caring, many families were left to face the loss of company of their family member at home (Moore & Dow, 2015). Although recognizing that health care professionals were looking out for the well-being and safety of caregivers and care recipients, families found that healthcare professionals underestimated the importance of the reciprocal relationship between family members and those in need of care (Moore & Dow, 2015) The form that family relationships take and the actions that LTC homes adopt to facilitate a meaningful role for families are significant issues for those with family members in LTC (Russell & Foreman, 2002). However, a constructivist hermeneutical study by Eika et al. (2014) that described and explored the experiences of families during the move of a relative into LTC using interviews with 10 family members found that family members are often unsure about what to expect from staff. Bramble et al. (2009) conducted a descriptive qualitative study about the experiences of family members that have placed a relative into LTC by interviewing seven children and three spouses and found that when staff had an understanding of a family member's need to remain involved and worked with them to establish their role in the home, family members were better able to maintain their previous identity and sustain previous relationships.

2.2.3 Staff Influence

Staff in LTC influence the extent that family relationships are fostered. The ways in which staff involve visiting family have an impact on the quality of visits for family members and residents, but these ways have been found to differ. Family members have been paid attention to, kept at a distance, been involved, and been controlled (Bauer, 2006; Westin et al., 2009). Having attention paid to them meant that families felt welcome and that they were seen as someone with the important role of visiting their family member (Westin et al., 2009). When family members were ignored, their encounters with nurses and visiting experience had a greater potential to end negatively (Almberg et al., 2000; Westin et al., 2009). Family members that were involved by staff during their visits were made to feel as though they were a significant partner in care and that they were a resource to the staff (Westin et al., 2009). When family members felt safe and secure during their visits, they felt respected and relaxed, they felt like they could be themselves, and they felt like they were part of a larger family (Westin et al., 2009). Despite recognizing the important role that visiting family members play in LTC, a qualitative study by Bauer (2006) that used a constructivist approach and interviews with 30 LTC home staff to examine how staff experienced working with residents' families found that LTC staff continued to perceive family as ancillaries to care and believed that residents and family members fell under their authority and control. LTC staff have also problematized family members and viewed them as recipients of care rather than members of the care team (Baumbusch & Phinney, 2014).

It is clear that staff in LTC play an important role in fostering visits that are meaningful for family members and residents. Working collaboratively with families to meet the care needs of residents in LTC aligns with nursing philosophy (Bauer, 2006), making the involvement of

family members a professional responsibility of nursing staff. Given the limited ability of residents in LTC to maintain family relationships and the role confusion associated with moving a resident into LTC, staff have a responsibility to acknowledge and involve family members with the intent to reduce confusion and allow for comfortable and meaningful visits that contribute to the fostering of family relationships. With the significance of the impact that staff in LTC have on the visiting experience of family members being apparent (Almberg et al., 2000; Maas et al., 2004; Westin et al, 2009), it becomes clear that visits are more than interactions between family members and those in need of care; they include an interplay between family members, residents, and staff.

2.2.4 Competing Demands

Despite the encouragement of staff involvement with family members, staff in LTC have been found to have their own competing demands as they balance expectations from family members and employers (Abrahamson et al., 2009; Hertzberg et al, 2003). Staff are required to manage multiple resident assignments and legally mandated responsibilities while attempting to meet employer and family expectations of individualized care (Abrahamson et al., 2009). This has resulted in staff being unable to attend to all the needs of family members and difficulty in fostering family relationships. Bauer (2006) affirmed that a task-focused model of care is not family-friendly and that the prevailing emphasis on tasks, routine, and activities of daily living stifles family involvement. Limited resources, increased resident acuity, shorter resident stays, irregular staffing schedules, and high staff turnover (Austin et al., 2009; Bauer, 2006; Hertzberg et al., 2003; Russell & Foreman, 2002) also make it difficult to fully engage staff with family members and residents. Nurses working in LTC have acknowledged their responsibility to ensure family members feel important and involved but felt as though residents were their first

priority and that family members often took time away from their work (Bauer, 2006; Hertzberg et al., 2003). However, it should be noted that nurses saw family members as a resource (Bauer, 2006) and have admitted to feelings of inadequacy when not having the time to attend to visiting relatives (Hertzberg et al., 2003). These same nurses appreciated visiting family members and their contributions to the well-being of residents. Adding to this appreciation, LTC staff have admitted to feelings of resentment and annoyance when families did not visit enough or appeared to show insufficient interest in their family member (Bauer, 2006; Baumbusch & Phinney, 2014). The forms that family relationships take in varying LTC contexts and the ways in which LTC homes facilitate family involvement and foster family relationships are important issues for the wellbeing and personhood of families and residents in LTC (McCormack et al., 2012; Russell & Foreman, 2002 Siegel et al., 2012).

2.3 Chapter Summary

In this chapter I provided a review and synthesis of literature on the attitudes that family members, residents, and staff have towards family involvement and the maintenance of family relationships as well as literature on the factors that influence the attitudes and efforts towards fostering these relationships. Quantitative and qualitative studies were included.

Moving a relative into a LTC home is associated with confusion over the new caregiving role that family members take and challenges in maintaining previous relationships and routines. With a lack of understanding and appreciation for previous family relationships and a focus on task-centred care due to time and resource constraints, staff in LTC are limited in their ability to foster family relationships. Without support and enabling physical and social environments, family members are left with the difficult task of maintaining family relationships in a context of misalignment between best care practices and available resources. Gaining a better

understanding of the importance that family members and residents place on family relationships and the factors associated with fostering these relationships can assist in gaining an appreciation for previous family relationships and the need to maintain them after a move into LTC.

2.4 Gaps in Knowledge

The ways in which relationships between family members and residents are fostered in LTC warrants attention. A gap in the literature exists, and current research that addresses the ways in which family relationships are maintained in this setting is needed. The facilitation of family relationships in LTC is necessary for person-centred care to be provided (McCormack et al., 2012), and with the growing literature on and broader culture-change movement towards person-centred care (Baumbusch & Phinney, 2014; Siegel et al., 2012), further study of contextual influences that promote or impede the implementation of person-centred care is needed (Siegel et al., 2012). An examination of the broader organizational context in LTC can help increase our understanding of the factors that contribute to the lack of time and attention currently given to fostering family relationship (Bedin et al., 2013; Moore & Dow, 2015). Critical ethnography seeks to expose existing forms of cultural domination found within organizational contexts (Thomas, 1993) and is therefore well-suited for addressing the research questions in this study.

Further examination of how family relationships are fostered in LTC is needed in order to go beyond the findings from other studies that simply acknowledge the importance of these relationships (Brown-Wilson & Davies, 2009; McCormack et al., 2012; Ryan & McKenna, 2015; Siegel et al., 2012). It is also important that studies that have explored the continued caregiving role that family members play in LTC (Baumbusch & Phinney, 2014; Bramble et al., 2009; Gladstone et al., 2006; Reuss et al., 2005) are not seen as studies that have examined the

fostering of family relationships. It cannot be assumed that having a role in care equates to the fostering of family relationships or that family relationships are maintained without support. This thesis project adds to the literature by exploring the ways in which family relationships are fostered in LTC.

CHAPTER THREE: RESEARCH DESIGN AND METHODS

3.1 Introduction

In this chapter I describe the research design and methods that were used in this study. This thesis entails analysis of data gathered as part of a larger critical ethnography examining how families negotiate their role in LTC. This methodological approach was chosen because of the complex social, political, and economic dimensions that exist in LTC and the ability of this approach to increase our understanding of the ways in which these dimensions affect family relationships in this setting. I will begin by providing a description of the methodology, study procedures, and sampling plan. I will then explain how data was collected and analyzed. Finally I will discuss the criteria used to ensure trustworthiness and rigor in the research process.

3.2 Methodology

Critical ethnography was used in this study and has become an increasingly recognized way of conducting nursing research (Baumbusch, 2011; Hardcastle, Usher, & Holmes, 2006). This methodological approach aims to raise consciousness and aid in emancipatory goals with the hope of effecting social change (Polit & Beck, 2012; Thomas, 1993). The use of interviewing and intensive and long-term participant observation conducted in critical ethnography creates a close relationship between the researcher and participant, helping the researcher to gain an insider's perspective of the topic under study (Parissopoulos, 2014). The researcher then aims to link the insider's perspectives to systems of domination, hidden assumptions, and ideologies as a means of empowering people and transforming political and social situations (Hardcastle et al., 2006).

The critical component of critical ethnography pushes the researcher to move beyond the immediate narrative of the participants to the broader social processes of cultural control in

which the narratives are embedded (Thomas, 1993). Critical ethnography uncovers what is normally concealed in other methodological approaches and attempts to change ways of thinking and provide evidence to counter accepted views (Thomas, 1993). When an appreciation for different views is developed and there is interest in showing how these differences mirror social problems, power, control, and suppression in the dominant culture, critical ethnography can be carried out (Thomas, 1993).

The historical, social, political, and economic dimensions of cultures along with their value-laden agendas are addressed when using critical ethnography (Polit & Beck, 2012; Thomas, 1993). Critical ethnography goes beyond traditional ethnography by possessing political, ethical, and social dimensions (Baumbusch, 2011), and this method of inquiry assumes that the actions and thoughts among a group of people are mediated by power relationships (Loiselle, 2011). This approach “gives body and presence to silent or less vocal representations of human behaviour and social life” and acknowledges the dominant ideologies that stifle other ways of understanding (Parissopoulos, 2014, p. 296). Given the existing power dynamics between families, residents, and staff in LTC homes and the complex social, political, and economic dimensions in LTC, a critical ethnographic approach was chosen for this study. This methodological approach is also particularly effective for researching health and social care provision in the setting where it occurs (Allen, 2004).

3.3 Research Questions

A critical ethnographic approach was used to address the following research questions:

1. How are family relationships fostered in LTC?
 - a. How do family members, including residents, foster relationships with each other in LTC?

2. How do the broader organizational and social contexts influence how family relationships are fostered in LTC?
3. How do socio-political locations (eg. gender, age, class, ability) influence how family relationships are fostered in LTC?

3.4 Study Procedures

This study draws on data collected in a critical ethnographic study titled *Inviting Dialogue on Experiences of Active Involvement in Long-term Residential Care (IDEAL)*². My study used a subset of the data that was gathered in a LTC home in an urban city in British Columbia, Canada. The IDEAL study examined how care is negotiated in LTC homes and aimed to better understand how supportive and collaborative relationships among families, residents and staff could be fostered to improve their health and well-being.

3.5 Setting

The IDEAL study took place in a LTC home in an urban city in British Columbia, Canada. The LTC home had 50 beds and received public funding from a local health authority on which it relied on to operate. All staff were employed directly by the LTC home (i.e. there were no contracted staff in this facility).

3.6 Participants

Participants from which data is collected provide the meanings that shape analysis (Thomas, 1993). It is therefore crucial to identify participants that possess an insider's knowledge of the research topic (Thomas, 1993). For this reason, purposive sampling was used in this study. Purposive sampling is a sampling strategy that selects participants that will benefit the study the most (Polit & Beck, 2012).

² The IDEAL study was led by Dr. Jennifer Baumbusch, principal investigator, Associate Professor, School of Nursing, University of British Columbia, and was funded by the Canadian Institutes of Health Research.

Inclusion criteria for family members were (a) that they had a family member living in the LTC home and (b) fluency in English. Inclusion criteria for residents were (a) that they lived in the LTC home and (b) fluency in English. Inclusion criteria for staff were (a) that they worked in the LTC home and (b) fluency in English.

Three groups of participants were included in the IDEAL study. The first group of participants consisted of 12 family members of residents living in the LTC home. Of the 12 family members, five were spouses, five were children, and two were identified as other. Three of the family members worked full-time, two worked part-time, and six were retired. The average age of their relatives living in LTC was 79 years (range = 73-85) and all with the exception of one had a main medical diagnosis of dementia. Their relatives had lived in the LTC home for an average of 24 months (range = 2-60). The second group consisted of three residents living in the LTC home, and the third group consisted of seven staff members working in the LTC home. This study focused on the data from family members only.

3.7 Data Collection

Data collection techniques included semi-structured interviews and participant observation. The use of multiple methods of data collection helps to develop a comprehensive understanding of the study topic and provides “an opportunity to evaluate the extent to which a consistent and coherent picture of the phenomenon emerges” (Polit & Beck, 2012, p. 590). The data for my study was collected by other researchers involved in the IDEAL study.

3.7.1 Semi-Structured Interviews

Semi-structured interviews allow the researcher to cover a list of questions related to their study topic while at the same time giving participants the freedom to provide as much detail or illustration as they like (Polit & Beck, 2012). Semi-structured interviews also allow the

researcher some flexibility in the questions they ask. Researchers conducting ethnographic research should look for answers that do not correspond to other participant's answers or that contradict observed reality (Thomas, 1993). By identifying these anomalies, new information can emerge through the use of follow-up questions (Thomas, 1993). Subtle follow-up questions in a critical ethnographic study can be crucial for digging below surface level responses that may be intentionally or unintentionally designed for the researcher (Thomas, 1993).

My study uses data from the 12 interviews with family members. Interviews were conducted in the LTC home in an area that was quiet and comfortable for the participants. All interviews were carried out with the same researcher, and relatives were present for some. Length of interviews ranged from 30 minutes to two hours. Participants answered demographic questions that gathered information on gender, age, ethnicity, education, and employment. Participants were then asked to talk about their involvement in the care of their relative in the LTC home through the use of semi-structured interviews. The interviews were tape-recorded and then transcribed verbatim. Interview participants received a \$10 honorarium in the form of a gift card.

3.7.2 Participant Observation

Participant observation aims to understand the behaviours and experiences of participants as they occur in their natural settings (Polit & Beck, 2012). These observations are characterized by prolonged periods of social interaction between the researcher and the participants in the participant's sociopolitical and cultural environment (Polit & Beck, 2012). The intensive and long-term participation of the researcher in the participant's natural setting allow for a close relationship to develop, providing the researcher with an insider's perspective and a crucial

component in critical ethnography (Parissopoulos, 2014). The immersion of the researcher in the field of study is an important characteristic of this methodological approach (Baumbusch, 2011).

Participant observations were carried out in the LTC home and field notes were taken during this time. Thirty-two hours of participant observation were conducted in various locations within the LTC home and included the dining room, a lounge, a TV room, the chapel, resident's rooms, a coffee shop, and an outside area of the home. Family members, residents, and staff were observed. My study uses the data from these field notes in addition to the data from the interviews conducted with family members, staff, and residents.

3.8 Data Analysis

A critical ethnographic approach requires the researcher to distance themselves from the taken-for-granted aspect of what they see during analysis and view this aspect more critically (Thomas, 1993). In critical ethnography, the researcher analyzes the power relations, beliefs, norms, and other forces that create an unequal distribution of social rewards, that “keep some people disadvantaged to the advantage of others, and block fuller participation in or understanding of our social environments” (Thomas, 1993, chapter 4, p. 11). In my study, the purpose was to further understand how family relationships are fostered in LTC. My analytic process required a critical look at the power dynamics and the organizational and social dimensions in LTC that influence these relationships.

Although data analysis usually begins from the moment ethnographers step into the field (Polit & Beck, 2012), I began thematic analysis following data collection. Thematic analysis involves discovering commonalities across participants as well as looking for variations among them (Polit & Beck, 2012). Themes that emerge through thematic analysis are never universal, making it necessary for researchers to pay attention not only to themes that arise but also to how

they are patterned (Polit & Beck, 2012). Because I was not part of data collection, I was not able to seek clarification of themes from participants simultaneously during data collection and analysis.

I began analysis by reading the interview transcripts and then continued to read the field notes from participant observation. I went back into the data as themes and patterns emerged and refined emerging themes as needed. As I read and re-read the data, themes were coded using NVivo 10, a type of qualitative data analysis software. These codes were then linked together into key categories and reflected the weaving of thematic pieces into an integrated whole (Polit & Beck, 2012). Interrelated themes were then reduced and regrouped into an overall structure (Polit & Beck, 2012) to aid in answering the research questions in this study.

3.9 Ethical Considerations

Care must be exercised to ensure that the rights of participants are protected (Polit & Beck, 2012). Ethics approval for the IDEAL study was obtained from the University of British Columbia Behavioural Research Ethics Board (UBC BREB).

3.9.1 Participant Rights

Study participants have the right to self-determination and the right to full disclosure, meaning that they can voluntarily decide whether or not to participate in a study, that they are fully informed of the nature of the study, that they are aware of the risks and benefits of the study, and that they can refuse to answer questions or withdraw from the study at anytime (Polit & Beck, 2012). Participants in the IDEAL study had these rights protected. Written informed consent was collected prior to conducting interviews and included consent for the audio taping of the interviews and dissemination of the study results. Informed consent means that participants

are given adequate information about the study, understand that information, and have the ability to consent to voluntary participation (Polit & Beck, 2012).

Participants also have the right to privacy, meaning that their anonymity is continuously protected and that their data is kept in confidence (Polit & Beck, 2012). Identifying information of the participants and the study site was removed during the transcription of interviews and writing of field notes. Data was stored in a secured online folder that was password protected. Data from the study will be stored for at least five years.

3.9.2. Participant Risk

Minimal subject risk was anticipated for all participants. There was the possibility of emotional distress for all participants as they recounted negative experiences in providing or receiving care. However, there was the likely benefit to all participants of having the opportunity to talk about their experiences that the interview questions explored. It is possible that family members might fear that their loved one would receive less care if they spoke negatively during interviews or participant observation. Residents might also fear that the care they received would be compromised if they spoke negatively about staff or the LTC home. In addition to residents and family, staff that spoke negatively about working conditions or the care provided might fear that they could be reprimanded by management for speaking this way. To address these concerns, all participants were reassured that the information they provided would be kept confidential and that in no way would the information they provide negatively affect the care provided or their evaluation as an employee.

3.10 Trustworthiness and Rigor

I used Lincoln and Guba's (1985) four criteria for increasing the trustworthiness of qualitative inquiry in my study: credibility, transferability, dependability, and confirmability.

3.10.1 *Credibility*

Credibility is thought of by Lincoln and Guba as an overriding goal when conducting qualitative research (Polit & Beck, 2012). Credibility refers to confidence in the truth and the interpretations of the data (Polit & Beck, 2012). There were a number of activities carried out to enhance the credibility of the findings and interpretations of this study.

The first activity that was carried out to increase credibility was prolonged engagement in the research setting. Prolonged engagement invests sufficient time in learning the culture of the group under study and building trust and rapport with participants (Lincoln & Guba, 1985). Prolonged engagement also increases certainty that the context of the study is appreciated and understood (Lincoln & Guba, 1985).

Member checking was a second activity that was carried out to increase credibility of the study and occurred during data collection. Member checking sees researchers providing feedback to participants as themes emerge (Polit & Beck, 2012). This feedback seeks to obtain confirmation from participants that the researcher's interpretations of participant realities are accurate (Polit & Beck, 2012). Paraphrasing and follow-up questions were used during interviews to ensure that the researcher understood what was being expressed by participants.

Peer debriefing was a third technique used to establish credibility. Peer debriefing is a form of external review in which peers that are experienced in the methodological approach or topic under study explore various aspects of the inquiry (Polit & Beck, 2012). My advisory committee looked for evidence of bias and reflexivity, errors of interpretations, and the weaving together of key themes and interpretations into categories (Polit & Beck, 2012).

Persistent observation was a fourth activity carried out to increase credibility. Persistent observation identifies characteristics and elements that are most relevant to the topic under study

and focuses on them in detail (Lincoln & Guba, 1985). While prolonged engagement provides scope in the study, persistent observation provides depth (Lincoln & Guba, 1985). This criterion required an ability to identify and focus on relevancies in the data, sort out the irrelevancies, and recognize when the atypical may be important (Lincoln & Guba, 1985). Persistent observation of the data was carried out alongside peer debriefing to help with identifying relevancies in the data.

3.10.2 *Transferability*

Transferability refers to the extent to which findings can be transferred or applied in other groups or settings (Polit & Beck, 2012). In order to meet this criterion, the researcher is required to provide a thick description of the time and context in which the study took place (Lincoln & Guba, 1985). The description provided enables an interested person to reach a conclusion about whether or not the findings can be applied to other groups or settings (Lincoln & Guba, 1985). A description of the participants and the study site were provided to meet this criterion.

3.10.3 *Dependability*

Dependability refers to the reliability of the data over time and conditions (Polit & Beck, 2012). This criterion challenges the researcher to conclude with findings that would be repeated if the study was replicated with the same or similar participants and context (Polit & Beck, 2012). As a way of increasing the dependability of the study, I kept an audit trail that included a description of the methods of data collection and analysis.

3.10.4 *Confirmability*

Confirmability is concerned with ensuring that the data represent the information provided by the participants and that the interpretations of the data are not invented by the researcher (Polit & Beck, 2012). A confirmability audit is a major technique used to establish

confirmability (Lincoln & Guba, 1985). The inquiry audit that helped establish dependability was used to enhance confirmability.

A second technique used to establish confirmability was triangulation. Triangulation uses multiple methods of data collection and analysis to sort out relevant from irrelevant information with the aim of converging on accurate interpretations of reality (Polit & Beck, 2012). Data was collected through semi-structured interviews and participant observation. These two methods of data collection increased the likelihood of achieving the overall purpose of triangulation; converging on the truth (Polit & Beck, 2012).

A third technique used to establish confirmability involved keeping a reflexive journal. Reflexivity is the process of critically reflecting on our personal values, biases, preferences and preconceptions that could affect data collection and interpretation (Polit & Beck, 2012). Reflexivity refers to an awareness of ourselves as part of the data that we collect and encourages us to be conscious of the potential of our own behaviour to affect the data we obtain (Polit & Beck, 2012). This process allowed me to reflect upon my own experiences and biases as a registered nurse working in LTC.

3.11 Limitations

There are limitations within this study. First, my experience as a registered nurse working in LTC has the potential to affect my interpretations of the data. My preconceived notions and biases of the setting may have influenced my analysis and reported findings. Second, I did not collect the data. This would likely have lessened the quality of my analysis, seeing that analysis in critical ethnographic studies start from the moment of data collection.

3.12 Dissemination of Findings

I plan to share the findings of my study with the researchers involved in the IDEAL study. I also plan to share my findings with the family members, residents, and staff in the LTC home that the IDEAL study took place in.

CHAPTER 4: FINDINGS

4.1 Introduction

In this chapter I present the findings from my study on fostering family relationships in LTC. Four themes were identified highlighting the ways in which family relationships are fostered in LTC. The themes were (1) multiple identities, (2) the role of the facility in fostering family relationships, (3) unanticipated complexities of fostering family relationships, and (4) efforts to foster family relationships in the context of LTC. The first theme reflects the overlooking of family identity and associated relationships when staff are unable to see the importance that families place on continued family relationships and the varying ways that family members maintain connection with their relative. Subthemes include *Long-standing relationships* and *Objectifying residents*. The second theme captures the impact of placement into a LTC home on family relationships. The third theme reflects the barriers that make it difficult to foster family relationships in LTC, given the cognitive and physical decline of residents and families' uncertainty as to how to spend time with a relative in care. Subthemes include *Physical and emotional impact of fostering family relationships*, *Cognitive and physical decline of relatives in LTC*, and *Challenges of making time together meaningful*. The fourth theme reflects the efforts made by family members and staff to foster family relationships and the importance to family members in doing so. Direct quotations from participant interviews and notes made during observations are used to describe the themes and sub-themes.

4.2 Multiple Identities

The first theme reflects the extent that residents in LTC were still seen as family members. All family participants knew their relative as a spouse, parent, sibling, or long-time friend and were committed to a continued family presence as a result of these long-standing

relationships. On the contrary, staff often overlooked the important family role that residents once played and continued to play, impacting the ways in which family relationships were fostered.

4.2.1 Long-standing Relationships

Family members cared for their relative prior to a move into LTC, and their commitment following the move continued. Family members expressed the need for their relative to be loved in the LTC home, similar to that experienced in previous family homes. When a 78 year-old sister was asked if the relationship between her and her brother affected the decision to be involved in care, the sister stated that there was “no doubt” about it and explained that she wanted to be “part of it” because she loved her brother (P10).

Family members talked about the connection they had with their relative and the need to maintain it after moving into LTC. A 72 year-old wife tearfully explained how she would love her husband until one of them died and described how important she thought it was for him to have a continued connection with her. She expressed her wish to have him at home but explained that their house was not equipped for the care that her husband needed nor could she afford to have somebody come into their home to care for him. This wife went on to describe the care she provided in the LTC home as a way to “keep connected” to her husband and to “still give him the love and care” that she would have at home (P2). Family members were given little choice in the options they had to keep their relative at home, given cost and equipment needs, forcing families to continue relationships outside of the family home. Despite this move, family members still saw their relative in their previous family role and wanted family relationships maintained. A 77 year-old wife explained that she and her husband had been married for 59

years and that she missed him at home. This wife stated that she wanted to come every day and admitted to missing the relationship she once had with her husband (P5).

Many family members expressed guilt from moving their relative into LTC and explained that they had tried to keep them at home as long as possible. One wife described the guilt and repercussions that families suffered from “because they had to” move their relative into LTC (P2). An 81 year-old husband described a “constant pain just under the surface” and at times feeling depressed about having his wife in LTC (P8). This family member talked about the relief he felt from having their family physician advise him that it was time for his wife to move into LTC, relieving him of making the decision to move her out of the family home.

Family members knew their relatives long before a move into LTC and continued to see them as an important and respected family member despite cognitive decline and a departure from their previous home. The expectations for dignity and respectful treatment did not change following a move into a LTC home, and family members continued to want the best of care for their relatives outside of the family home. Residents were still seen as a spouse, parent, sibling, or friend by their family members, and the commitment that accompanied these family relationships was evident in the interviews.

Family members demonstrated this commitment partly by advocating for their relatives. Although the long-standing family relationships and accompanied commitment were not always understood by staff, family members continued to demand the best of care for their relative. One wife explained that she advocated for her husband, because she wanted “to make sure that the things that need to be done are done”, despite the resentment that she felt from some of the staff towards her involvement in care (P2). A 70 year-old wife stated that she did not want to be “the enforcer” when it came to advocating for her husband, but admitted to having to take on this role

(P3). A staff member acknowledged the stress that family members felt from the responsibility of having to maintain a family relationship in a LTC home while also ensuring that their relatives were “still alive” and treated with the best of care (P20). This same staff member expressed an appreciation for family relationships by referring to residents as family members.

Although this staff member was able to acknowledge residents as family members, not all staff appreciated the value placed on family relationships and connection. A wife that visited her husband five days a week came in to “do all the extra things” that would “make the journey easier, or more comfortable” for her husband with dementia, but she explained that staff had told her that her husband would not know if she visited. She expressed doubt in this argument:

I don't know. But there are moments, like earlier, when I came in and he was sitting there, and I just went, “Hello, sweetie,” and he just looked at me and beamed. So I think there are little moments of cognition. (P2)

The reciprocity of family relationships was not always understood by staff. During an observation, field notes were taken while spending time with this same family member and her husband. The researcher wrote, “FM0102 grips R0103's hand between hers. ‘People say to me, you don't have to visit every day. You can leave and he wouldn't miss you.’ She pauses, and then adds, ‘but I would miss him’.” Although she did not disagree with this suggestion, she stated that despite the possibility of her husband not missing her, there was certainty that she would miss him (P2).

Family members described their ability to see the connection that their relative was still able to maintain with them, but family members found that staff were not always able to appreciate this connection. One wife explained that staff often think residents “don't realize what's happening” but suggested that “they're there” if you look into their eyes, giving credit to the ability that residents have to maintain a relationship (P4).

4.2.2 Objectifying Residents

Family members described their observations of staff having to get their work done on time before they went home at the end of the day and the lack of time spent connecting with the residents. Residents became objectified by staff as they completed their required tasks. A wife stated:

If you gave him something and just said hello to them a little bit in a friendly kind of... in a way that you were more like their child and you were bringing them something because they were mom or dad or something like that. You sensed that was what they were missing in their life, not a peer. (P3)

One staff member talked about the high turnover rate of residents and the expectation from staff that residents in the LTC home are “going to die very soon” (P22). The staff member explained that care staff were learning to distance themselves from residents and families so as not to develop any kind of close relationship with them. A sister further described the environment in the LTC home as sterile and one in which there aren’t a lot of surprises. She discussed how she would like staff to have more of a connection with residents so that they were part of a community that was “still involved in life” (P10).

Family members did not want their relative to be seen as a task to be completed, and they questioned the ability and the willingness of staff to acknowledge the connections that residents were capable of experiencing. One daughter described how she would like staff to treat her father with dignity and see him as a “man that contributed.” She stated, “I want them to see that he's my father and that I love him” (P12).

4.3 The Role of the Facility in Fostering Family Relationships

The second theme reflects the impact that placement into a LTC home had on family relationships. Family members described examples of time taken away from simply being a

family member and alternatively spending time filling in gaps in care. Family members also described the changes they experienced in spending time with their relative.

Family members expressed the need for more care staff. A wife compared the care provided in a previous home to the care currently being provided to her husband:

But I was the family. I could be the wife up there, the visitor. I didn't have to be...I have to be another staff person essentially. So that's what I would like to have, that load taken off, because I would be better and more caring of [R0110] if I didn't have this workload on top of the actual delivery of the service as well. (P3)

Family members were found to have to follow up on changes in care for their relative, and improvements in communication were wanted by nearly all family participants. A 53 year-old daughter suggested that a quarterly report on residents be sent via email to improve communication. This daughter stated that a monthly financial statement was sent to families and questioned why a report on how their relative was doing could not be sent as well. This suggests alternative or non-traditional ways of keeping residents and family members connected and contributes to fostering family relationships outside of the home. Many family members expressed frustration as they took on an advocacy role for their relative and were left with less time to be a family member. One family member explained how playing the role of her father's advocate took time away from her role as a daughter:

Well, I'd like them to communicate better with me so I didn't have to be an advocate all the time. I don't want to be an advocate. I want to be a daughter. They've robbed me of being a daughter. I do believe that because now I have to be front and centre. I can't just love him. I have to protect him. I have to do the follow-up work. I have to make sure that they do the right tests that are needed, that they take the fact that he's losing colour seriously. I have to... yeah, I want to be his daughter. I don't want to be his advocate. (P12)

There was little mention throughout participant interviews and observations of activities that purposefully involved family members in the LTC home and a complete lack of activities that fostered family relationships. Families were often present at meal times, but their assumed

role was to assist with feeding their relative, resulting in them playing more of a staff role than that of a family member. Activities that were once shared and enjoyed by family members and their relatives were not recognized or supported. A daughter discussed the challenges in participating in activities that were enjoyed by her father. She stated that the LTC home did not support or encourage families to do the things that they normally would have done and described the home as a prison. She explained that the staff will tell you what can go wrong, but they won't give you the tools or the skills to address the problem (P12). The LTC home had created an environment that was not conducive to fostering family relationships, largely because of a lack of activities or places in which families could continue to be family members.

4.4 Unanticipated Complexities of Fostering Family Relationships

This theme reflects the barriers that made it difficult to foster family relationships in LTC given the cognitive and physical decline of residents and the uncertainty as to how to spend time with a relative in care. Traveling distances and outside family and career responsibilities contributed to caregiver fatigue and resulted in feelings of frustration and guilt when family members were not able to spend the quality or quantity of time with their relative. The cognitive and physical decline of residents made it difficult for family members to engage in conversation as well as participate in activities outside of the home, leaving families to foster relationships with their relatives within the LTC home. Some family members described the challenges they had or their other family members had when trying to engage with their relative, making it difficult to maintain a connection. These challenges created barriers to fostering family relationships and prevented some family members from coming into the home.

4.4.1 *Physical and Emotional Impact of Fostering Family Relationships*

Family members visited their relative out of love, guilt, and feelings of obligation, but they also described the physical and emotional impact their commitment to their relative had on their health. A 53 year-old son expressed both the guilt he felt when he did not spend enough time with his mother and the frustration he experienced from the amount of time and effort required to see her in the home. He stated, “Like, the amount...it’s such a high maintenance thing, this whole looking after her, right. And it takes up so much time, so much people’s time, so much of my time” (P11). Family members also had competing family demands and outside responsibilities, but the commitment to a relative in LTC was still present. This same son described his career and outside family responsibilities and admitted to being overwhelmed at times, but stated, “I got to go do this for my mom” (P11).

During an observation, one family member complained of being “tired, always tired” (P1). This family member visited her mother once every weekday and twice on the weekends. A daughter also described the fatigue she felt as a result of the commitment to her father:

So that's one of the reasons I asked for Dad to be moved back into [Health Authority 3] because traveling, trying to work and travel is a bit much. But I think I have burnout now after doing this for about three years, and so I'm slowing down my... I'm letting go of my business that I've operated 35 years, which I'm sad about. But I think that looking after my parents is more important. (P12)

Some family members had been advised by physicians and staff in the LTC home to lessen the extent of their involvement in order to better look after themselves. Some family members followed this advice while others continued with their regular routine of visiting. This was evident during an observation with a family member and her husband:

Observer said that it must be difficult. FM0102 nods, and then states that, “I spent 11 hours here the day before, as he was sick. You see people who pop in for 20 minutes, if that. I had a little counseling session with S0102 a week or two ago, and she asked me, “What makes you come every day?” And I told her, it is guilt. Absolutely. It brings you

to a standstill when you have to put them in a care facility. Guilt drives me every day.” FM0102 discusses the toll this has on her, saying, “I sometimes am so exhausted I have sleepathons. Once a slept a whole day away. A whole entire day.

Another wife described the time spent with her husband and stated “somehow I’m exhausted by the time I get home” (P4). The fatigue, ill health, and stress that family participants attributed to their involvement and commitment to their relative in LTC often resulted in family members spending less time than they would have liked in the LTC home connecting with their relative.

4.4.2 Cognitive and Physical Decline of Relatives Living in LTC

Family members knew that their relatives with dementia were walking through a “one way door” when they moved into LTC and stated that although it wasn’t a prison, it was a “facility from which you’ll never emerge” (P8). One wife knew that her husband was “never, ever going to get better” and admitted to feelings of distress from “seeing him a little worse every day” (P3). Maintaining a conversation became a challenge as residents with dementia progressed in the disease, making it difficult for relationships to be fostered. A 48 year-old daughter stated:

You know, we sat at Coffee Shop 1 yesterday and I propped her in front of the window, and you know, the traffic's going by, there's people on the seats outside on the other side there, chatting away. I mean it just... I mean what do you do at that stage? Yeah, it's not like she can keep a long conversation going. (P1)

One sister explained the challenge of interacting with her brother and how his decline kept them from continuing to broaden their horizons together. She saw her brother as being in “his own world” and described the difficulty in involving him and making the connections that they usually made (P10). This same family member acknowledged the fact that relatives with advanced dementia cannot always have conversations and questioned why the LTC home did not provide internet access to families as a way to engage with residents in other ways. Family members referred to the changing nature of dementia and the need to adjust the relationships

with their relatives in order to account for cognitive decline. Relatives were seen as being in “some other stratosphere”, and there was a sadness that was associated with this change (P10). Stories about ways in which family members used to interact with their relatives were shared, but one family member stated, “We have to recognize that that’s going to happen and be prepared for it” (P10).

A 77 year-old wife also discussed the need to adapt to the cognitive changes that occur in people with dementia, and explained that her son had a hard time adapting and found it difficult to come in to see his father. She described the hockey and baseball games that her son and husband used to attend together and how they were no longer able to attend those events:

And then they had hockey tickets and stuff like that. So it's a big adjustment...And they went lots of times to City 18 to watch baseball, you know, a bunch. They always included R0111 which is nice, you know? But things change and you've got to change with them, right? (P5)

One daughter further described the changing nature of the relationship with her father:

Yeah so I still know he's there, but yes our relationship is completely changed, and yeah. It's hard for him to have me as his caregiver and advocate, it is, because that was his role. [Weeps] He was my mentor. He was my go-to guy and I would talk to him about business, and he looked after his own extensive real estate portfolio and his law practice. But all said now, not only have I lost my best friend, my mentor, my business partner, but I've had to take on his life and mine, and look after him, and battle this establishment. [Cries] Like, what is going on? Yeah and... it's just unbelievable. Yeah. It's just so sad. [Weeps] (P12)

References were made to the changing family roles as some family members now viewed their parents as children, adding complexity as to how previous relationships could be maintained. A daughter discussed the ways in which she cared for her mother and stated, “You know, she’s almost like my child” (P1). Family members acknowledged the loss of memories and identity that accompanied dementia. One husband explained that relationships depend on the identity of individuals and that memory maintained these identities. He stated, “When our

memories are gone, we are nobody. That's the devastating thing about dementia is in effect it's a living death, because once those memories are gone...who are you?" (P8). A staff member described the difficulty in adapting to the changing relationship that she had with her father that was diagnosed with dementia:

It's hard. It's already hard enough to have to... you're watching your family member – especially with dementia, right – turn into this totally different person. And it was very tough on me, like my dad was always my hero that could do every single thing. And then to have to not even have anyone alongside us it was just, I don't know, it was really very, very hard. (P20)

During participant observations, family members were observed during time spent with their relative. Daily experiences with relatives were reflected on, and residents were often found to be “quite distant from the reality of their visits” (R). During another observation, the researcher noted the lack of knowledge that one family member had about dementia and the frustration he felt while trying to maintain a relationship with his mother. After the observation she reflected on her interest in observing family members that were at a loss as to what to do when spending time with their relative. The researcher explained:

Outside of R0115's room I chatted with FM0111 and Grandson 2. “I just don't know what to say to her,” FM0111 admitted. I nodded in response. “And I don't know what's wrong with her, if she's upset; or what, but she never used to swear... I explained that it probably is just the progression of her dementia – that many people with dementia lose their filter and will swear more. FM0111 seemed shocked and said, “I had no idea! I thought it was just her, something I was doing, or something. It's just the disease?” I nodded again. “Well, that's good to know,” he said.

Lack of recognition of family members was another factor that made it difficult to spend time with a relative in LTC and continue having a relationship. A 58 year-old daughter described the “tough time” that her brother had dealing with their father's cognitive decline. She explained that he had a hard time accepting the change and stated “because, you know, my dad doesn't seem to recognize him, and he just looks blankly at him” (P6).

The cognitive decline of other residents had an impact on the social environment in the LTC home. Many of the residents observed had minimal interaction with each other, engaged in socially inappropriate behaviour that included disrobing, called out repeatedly, were unable to speak, and presented as physical threats to other residents and staff. A wife that came in to visit found her husband and another female resident walking together:

And I'd find the two of them walking up the hallway hand in hand. I'd be in tears, thinking... but he was with her more than he was with me now, right? So one day the elevator door opened, and there are the two of them standing, holding hands, looking into the elevator, and I said, "Oh, hi, R0103. Hi, R0106. How are you today?" And she said, "Oh, my husband and I, we're going downstairs." (P2)

This wife expressed her understanding of the changes in behaviour, but she explained that they were still married and that there was a huge part of her heart that would not accept the situation. She stated that she still loved him but that this was "almost like cheating" (P2).

4.4.3 Challenges of Making Time Together Meaningful

The visiting experience varied for family members, and some were more comfortable than others. A wife that visited on an almost daily basis described the feelings her son had towards spending time with his father in the LTC home. She stated that her son was terrified, because he feared similar cognitive decline might happen to him. Despite talking about there being no guarantee of this happening, her son was still reluctant to come into the home.

Family members had to deal with challenging behaviours as the dementia in their relative progressed. These behaviours included false accusations, restlessness, resistance to care, and requests to go home, and for many family members, recognition from their relative no longer occurred. Family members admitted to feeling tired from the emotional input required. One husband explained the difficulty he had with visiting his wife:

(P8) Ever since she's been in care, I've never been able to spend more than a couple of hours with her, simply because it's too... too devastating. It's too hard to see her the way she is.

(R) Um hmm.

(P8) It's emotionally too wearying. I can't sort of ignore that. I can't put that on one side and say I can stay here with her.

A daughter also described the difficulty she had with visiting her mother and stated that she was unable to cope emotionally with visiting her every day because of her mother's repetitive calling out and anxious behaviours. She instead had chosen to visit every other day and sometimes twice a week. During an interview, another daughter described her encounter with a visiting family member. She explained that there were only four family members that regularly visited the neighbourhood that her husband was in and stated, "Everyone else, like, you barely see. I feed the lady next to my mom. Her daughter came at Christmas and said, 'I hate coming in here,' in front of her mom" (P1).

Family members discussed the additional challenges in finding activities that their relative enjoyed doing. One husband walked with his wife around the neighbourhood and took her out in their car when she first came into LTC, but as his wife's physical ability and cognition declined, outings required a wheelchair and were reduced to shorter distances. Mind games and Bingo were no longer options for this family member's wife as her cognitive ability and loss of speech no longer allowed her to understand the games.

A daughter further described her challenges in finding activities that promoted her father's dignity and a continuation of the past. She explained that they no longer spoke the same language, although they spoke "dementia now." She stated:

He used to love to go out for walks, but he's afraid now. So I brought in a wheelchair; hopefully he'll find some security in the wheelchair. [Voice shakes] But no, there's nothing that we do as a family anymore, nothing. He's lost all his dignity and he's lost all connection. (P12)

Driving distances, careers, and outside family responsibilities also prevented family members from visiting as often or as long as they would like. One wife commuted two and a half hours to visit her husband. Another family member explained that full-time work, two young boys, and a long commute prevented her daughter from visiting more often, despite her daughter wanting “to be more connected” (P10). A son explained the “hassle” he went through to visit his mother and the fact that it was a “drag” to get to the LTC home. He stated:

Originally I was kind of disappointed and kind of pissed off about not being able to get her to [Neighbourhood 4], right. Because I wanted to visit, and I wanted my kids... and I don't want to have to drag... try and drag my kids and my wife and see my mom somewhere else. It was bad enough going to [Neighbourhood 3], which is not that far of a drive. But it's a long time, it took me 45 minutes to get here today from [City 23]. That's a long time, right. (P11)

4.5 Efforts to Foster Family Relationships in the Context of LTC

This theme captures the efforts made by family members and staff to foster family relationships and the importance to family members in doing so. Family members were observed to have hung pictures in resident's rooms with the intent of reminding their relative of family presence. Family members also engaged in activities that included their other family members, fostering family relationships in the process. Staff members were also found to have thanked and acknowledged family members for their time and presence. In an attempt to foster a relationship with her father, a daughter expressed her concern that her father would not be treated with dignity and would not be seen for the person he was. She described the family poster she had made for the staff and stated:

Because I want them to see who he was, to respect him for the man because they forget that. [Cries] These care workers and these doctors and social workers, they forget that he was a human being and not just... I don't know what they think, a patient. A patient, like what is a patient? And so I put this together and I put these boards together with who he was as a young man, his family, his career, and not who he is today. (P12)

Family members carried out activities or helped in ways that they felt comfortable with. Some family members assisted at meal times while others took their relatives for a walk. A sister created a family newspaper that kept other family members involved. She explained:

But they would send a story every week – something that they've done, something of interest. We try to avoid memories of how great he was and how muscular he was and all of the wonderful things he used to do, but just on the present and things that they share with him....So it really adds a lot to my ability to connect with him because we don't want to leave them out. And we can talk about them and when they're coming and what they're doing right now... you know, to keep him into the family picture. (P10)

Resident's rooms were observed to have family pictures hung on the walls. One family member had a calendar with a picture of her relative's grandson for each month of the year. The kitchen in the LTC home also planned a bistro night to encourage family involvement and act as a means for residents to invite their family members for dinner. Signs of affection were shown between family members during interviews and observations as hands were held and arms were touched. During an observation the researcher described a husband walking with his wife and stopping to hug and kiss her. Other family members were also involved with the physical care of their relative, and one wife described it as a way to connect with her husband.

One staff member talked about wanting staff to “reprioritize what's really important around the resident's clock” and take more time to be present with residents and their family members (P22). She explained:

I do my best to the families and the staff that, "Their brain is still active. They will hear everything, so if you want, you can hold their hand. You can tell their stories about the memories that you shared together. You can read a book." Or if a person is in very advanced dementia and you don't think that person is there, that person is there. "This is a difference I saw in the colour of their face when you are here versus when you are not." (P22)

This staff member highlighted the importance of family presence and letting family members know that they make a difference in the everyday lives of residents. This staff member

acknowledged the busy lives that family members have outside of the home and the need to provide positive feedback to families as a way to encourage them to come into the home and continue to foster relationships with their relatives.

CHAPTER 5: SUMMARY, DISCUSSION OF FINDINGS, NURSING IMPLICATIONS, AND CONCLUSIONS

5.1 Introduction

In this chapter, I provide a summary of the study and a discussion of the key findings in relation to my research questions and the context of existing literature. The implications for policy, education, and nursing practice are presented, as well as the conclusions drawn from the study.

I conducted an analysis of qualitative data collected as part of a larger critical ethnography focused on how families, residents and staff negotiate care work in LTC settings. My study used a subset of the data that was gathered in a LTC home in an urban city in British Columbia, Canada. The sample consisted of 12 family members, seven staff members, and three residents. This study focused on the data from family members only. The aim of my study was to further understand how family relationships are fostered in LTC.

5.2 Summary

The first theme that was identified was multiple identities, and it reflected the extent that residents in LTC were still seen as family members. The first theme incorporated subthemes of long-standing relationships and objectifying residents. The second theme was the role of the facility in fostering family relationships, and it reflected the impact that placement into a LTC home had on family relationships. The third theme was unanticipated complexities of fostering family relationships, and it reflected the barriers that made it difficult to foster family relationships in LTC. The third theme included physical and emotional impact of fostering family relationships, cognitive and physical decline of relatives living in LTC, and challenges of making time together meaningful as subthemes. The fourth theme that was identified was efforts

to fostering family relationships in the context of LTC, and it captured the efforts made by family members and staff to foster family relationships and the importance to family members in doing so. In summary, family engaged in fostering family relationships in a complex context.

5.3 Discussion of Findings

As the findings of this study show, residents in LTC and their family members face challenges to maintaining and fostering family relationships. Influences both inside and outside of the LTC home created opportunities and obstacles to maintaining these relationships. However, the limited support and guidance given to fostering family relationships in LTC resulted in the number of obstacles outnumbering the number of opportunities. I will discuss the findings of this study in relation to (1) how the fostering of family relationships contributes to the maintenance of personhood and how family members in LTC foster these relationships, (2) how the broader organizational and social contexts influence how these relationships are fostered, and (3) how socio-political locations (eg. gender, age, class, ability) influence the fostering of family relationships.

5.3.1 Fostering Family Relationships to Maintain Personhood

The commitment and effort to maintain family relationships was partnered with the purpose of preserving dignity and ultimately the personhood of a relative in LTC. Activities for residents and their family members that provide a shared sense of who they are as a family contribute to the sustaining of family relationships and support the personhood of people with dementia (Phinney et al., 2013). Family members were committed to keeping their relative included in the family, and many expressed doubt in the ability and willingness of staff to preserve family roles and identities of residents in the LTC home. It was evident that the physical and cognitive decline of the residents in this study further contributed to the complexity

of maintaining the personhood of a relative in LTC. As previous roles and identities became a challenge to maintain for those living with physical and cognitive impairment in the LTC home, family members were committed to having their relative still be seen as a respected family member. The facilitation of family relationships not only recognizes a resident's place in community, it enhances their personhood and celebrates their identity (McCormack et al., 2012). Considering that personhood is based on relationships with others (Penrod et al., 2007), it is important that family relationships be fostered in this setting.

It was clear that family members wanted to foster family relationships in the LTC home. The underlying commitment and continued ability to see a relative in LTC as an important family member resulted from long-standing relationships. Relatives were still seen as spouses, parents, siblings, and friends and family members made many efforts to maintain these identities.

Family members often came into the LTC home to assist their relative at mealtimes and take part in activities that were planned by the recreation department, both of which were resident focused and did not consider the involvement of family. Outside activities included walks in the garden or walks onto a different floor, but neither of these activities were specifically designed to include families or foster family relationships. While these activities kept family members and residents occupied, as there was often uncertainty about what to do while spending time in the home, there were no plans or intentions from staff or the LTC home to attend to the connections between family members and their relatives in care. Gratitude and appreciation were expressed by staff for the assistance provided from family members during these times, but acknowledgement of family roles and intended efforts to foster family relationships during a family member's time in the LTC home were not made.

Efforts to involve residents in activities that were once enjoyed and still familiar to them can further contribute to the fostering of family relationships by allowing family members to relate to their relative in familiar ways (Phinney et al., 2013). Family members discussed the challenges they had with finding ways to spend time with their relative, and outside of the bistro night that invited family for a meal, families were left to continue previous relationships on their own. The lack of opportunity for residents and family members to engage in activities that acknowledge previous relationships goes against current research that identifies the most important activities for people living with dementia are those that are meaningful for the family as a whole (Phinney et al., 2013).

5.3.2 Organizational Context

The broader organizational context of the LTC home influenced the fostering of family relationships. Family members spoke of the task-focused care in the home and at times battled with staff to have their relative seen as a respected family member. Despite the efforts made by staff to acknowledge family presence, the need for ongoing family connections and the recognition of important family roles were often overlooked, leaving families to maintain these connections and roles without support or assistance. This goes against previous research that identifies staff in LTC as playing an important role in facilitating and supporting relationships between residents and their family members (Mendes, 2015).

Part of this lack of support and assistance can be attributed to the amount of necessary administrative tasks and paperwork that has created a gap between the reality of care provided and a vision of what ideal care should look like (Bedin et al, 2013). The shift from the current provision of task-oriented care to one that entails a relational approach is difficult considering that relational care is not something that staff have learned how to incorporate into their practice

and an approach that they do not get rewarded for. This has resulted in tensions among care staff over how time should best be allotted to residents and their family members (Bedin et al., 2013). Continual change, multiple relationships, and contradictory philosophies of care have also been found to add complexity to the context in which LTC is provided (Cammer et al., 2014), resulting in uncertainty as to how staff should be spending their time with residents and family members.

Geographical distances were also found to have influenced the fostering of family relationships. Residents were not always placed in their preferred home, resulting in driving distances that were not conducive to the schedules of many family members and less time being spent with their relative in LTC. There were no stated efforts made to foster family relationships outside of the LTC home, including a lack of effort to coordinate transportation or communication via telephone or Internet. This placed full responsibility on family members to maintain connections with their relative within the home.

A lack of policies in LTC that support the role and identity of family members further challenged families to maintain relationships. This is consistent with previous research that highlighted the possibility of conflicting ideas from administration and staff about the role of family members in LTC (Baumbusch & Phinney, 2014). Despite the significance of family relationships for most family members and the substantial contribution that families make to the quality of life of residents in LTC, there is little guidance concerning their role (Ross et al., 2001; Wright, 2000). The lack of support for family members and a lack of activities that engaged families with their relative stopped many family members from coming into the LTC home. Given that visiting can be seen as both a “task to be performed and the context for continuity of family relationships”, LTC homes need to develop policies and programs that allow for the time

spent with relatives in care to be as enjoyable and meaningful as possible (Ross et al., 2001, p. 358).

5.3.3 Social Context

Cognitive and physical decline were found to significantly impact the social environment of the home as well as the relationships between residents and their family members. Health and mental health conditions have been reported as common barriers to nurturing relationships, and living in a LTC home can have “substantial impact on the context, quality, and nature of social relationships, with the greatest impact stemming from the level of health decline and functional limitations among facility residents” (Bonifas, Simons, Biel, & Kramer, 2014, p. 1335). The authors found that building or maintaining relationships in LTC is challenging due to the medically compromised nature of the residents.

In the same study by Bonifas et al. (2014), resident participants found that their friends withdrew from them after a move into LTC. The participants believed this was due to their friends wanting to avoid reminders of their own potential decline in physical and mental health and uncertainty as to how to engage in social interaction given each resident’s own health declines and associated disabilities. Family members in my study described similar concerns on behalf of other family members and contributed their fears about potential health decline and uncertainty as to how to spend time with their relative in LTC as reasons for not coming into the home. Family members from other studies have also described their time spent in LTC as difficult and have explained that the time spent with their relative in their previous apartment or home was much more comfortable than visiting in LTC (Strang et al., 2006). Jablonski, Reed, and Maas (2005) found that “family caregivers may be unsure as to how to maintain their

relationship with the institutionalized individual, and may inadvertently withdraw from the relationship, hastening the resident's functional and cognitive decline" (p. 41).

The loss of these long-standing relationships and social roles weaken a resident's preservation of self (Surr, 2006). In addition to the undermining of self, the loss also narrows the social context within LTC as residents have limited contact with the social world outside of the home (Surr, 2006). This lack of contact with the broader society resulted in the majority of significant relationships being lived out within the narrow social context of each LTC home (Surr, 2006). Family members in my study also found it difficult to spend time with their relative outside of the LTC home due to physical and mental decline and challenges with organizing outings without the assistance from the home. Further to the narrowing of social context, admission into a LTC home requires the move from one's familiar home environment into a foreign social environment, requiring the establishment of new relationships for both residents and their families (Ross et al., 2001). Family relationships continue although in a different form and setting (Ross et al., 2001).

Family members in the study frequently discussed the changing nature of family relationships. This was largely affected by mental and physical decline, but references were also made to the lack of opportunities and support in finding ways to connect with their relatives. Although a lack of privacy in the home was not specifically stated as a concern for fostering family relationships, time spent with relatives was often interrupted by the disruptive behaviours of other residents. These disruptions and a lack of private settings within the LTC home align with previous research that acknowledges the difficulty in spending time with relatives because of a lack of privacy (Hertzberg et al, 2003; Wright, 2000).

In addition to the changing identities of residents in LTC due to cognitive and physical decline, the identities of family members were also challenged. O’Conner (2007) found that health care professionals acted as external sources in the social construction of family members as caregivers, adding to the risk of family identities being removed. Identifying family members as caregivers contributed to the positioning of family members as such and influenced the ways in which time was spent with their relative (O’Connor, 2007). Family members in the study by O’Connor described themselves as both family members and caregivers as a way to make sense of who they were. One participant in the study described family members as having to wear two hats; one being a family member, and the other being that of a caregiver. Findings from my study also found that family members were often removed from their title of spouse, parent, or sibling and put into a position of advocate or care staff. Time spent helping with and following up on the care provided in the home took time away from family relationships being fostered.

5.3.4 Socio-political Locations

There are socio-political locations that influence the fostering of family relationships. Although participants did not directly state that gender affected their involvement in care, the majority of participants were women. Many of the wives and daughters in this study provided personal care to their relative and discussed the amount of time spent monitoring care in the home. While female family members may be willing to carry out caregiving responsibilities, it may not occur to women that they were doing something outside of their relational role as a wife or daughter (O’Connor, 2007). This was found to be more apparent for wives, where it was easy to see the care that they provided as part of their normal role (O’Connor, 2007). While there was one wife in my study that described the personal care that she provided as a means to

maintaining a connection with her husband, it cannot be assumed that this was how female family members fostered relationships with their relative in care.

Family members that spent the most time with their relative in care were spouses and older children that were not working or were retired. These family members talked about the outside commitments and responsibilities that their younger family members had that prevented them from coming into the home as often as they would have liked to. Class and ethnicity were not found to have an influence on fostering family relationships in LTC, although having or not having a paid companion may have reflected education and income status and affected family involvement and caregiver fatigue. Participants in this study were not directly asked about the influence of socio-political locations on their involvement in care with their relative or its influence on fostering family relationships. Findings may have been different if family members were directly asked about and given time to reflect on the influence of socio-political locations.

5.4 Nursing Implications

My intent for this research study was to further understand and raise awareness of the importance of fostering family relationships in LTC with the overall aim of improving the quality of resident care.

5.4.1 Nursing Policy

Improving the physical and social environment of LTC homes in ways that contribute to the fostering of family relationships would benefit the ability of family members to sustain connections with their relative in care. Incorporating family-centred care into nursing policies and encouraging the caring for residents and family members as a unit as opposed to separately would further foster family relationships. Family-centred care, or relational focused care, recognizes the relationships between residents and their family members and sees these

relationships as the key to providing better care and developing improved policy and practice (Morhardt & Spira, 2013). There is currently no stated policy that addresses the fostering of family relationships in the LTC home that this study took place in, and it is unlikely that this type of policy exists in other homes. It is important that those working in LTC begin to recognize the value of family relationships and explore ways of incorporating family-centred care into everyday practice.

5.4.2. Nursing Education

Based on the findings from the interviews and observations with families, staff played a minimal role in fostering family relationships. While family-centred care needs to be enacted in all care settings, an emphasis on maintaining family connections in LTC is needed, seeing that this setting becomes a permanent home for each resident and is one in which family relationships should continue. An understanding and awareness of the value placed on the continuation of family relationships and the need for support in fostering these relationships should be brought to the attention of all staff during initial hire and on a regular basis following hire so that respect and appreciation for family relationships and family identity become part of each LTC home's philosophy of care.

5.4.3 Nursing Practice

Family members in this study spoke of the need for more opportunity to engage in activities to foster family relationships with their relative, highlighting the need for nurses to better attend to the social needs of those caring for someone or living in LTC. Having the necessary frame of mind to understand and welcome the feelings of residents and family members and appreciate what they are going through (Bedin et al., 2013) can improve the ability of nurses to foster family relationships. Considering that the majority of family members view

staff in LTC as a major source of learning (Ross et al., 2001), nurses need to find time to educate families on the changing nature of dementia and support them in finding ways to maintain a connection with their relative.

5.5 Limitations

This study included family members, staff members, and residents from one LTC home, but the majority of participants were family members. An increased number of resident participants in the study would have helped to better understand the barriers and facilitators that residents encounter when fostering family relationships. The majority of participants were Caucasian, and all were English speaking; a higher inclusion rate of other ethnicities would have reflected the perspectives of the large immigrant population currently accessing LTC in Canada (Baumbusch & Phinney, 2014). Although this study explored the ways in which family relationships are fostered in LTC, participants from the IDEAL study were not specifically asked about this concept. Some participants spontaneously talked about maintaining family relationships and their own and other family roles, but findings may have been different had specific questions been asked about the ways that family members, staff, and residents foster family relationships in LTC.

5.6 Recommendations for Further Research

The findings of this study highlight the limited effort made by this LTC home to foster family relationships. Further research on the ways in which these relationships can be fostered both inside and outside of each home is necessary to better enact person-centred care with the use of family-centred care.

5.7 Chapter Summary and Conclusion

In this chapter I discussed the findings of my study in relation to my research questions and the context of existing literature. I presented the nursing implications for policy, education, and nursing practice and made recommendations for further research. The implications addressed the importance of fostering family relationships in LTC and the need for support and assistance in doing so.

LTC homes should not underestimate the value that family members place on the ongoing relationships with their relatives in care. With family members facing challenges that include uncertainty about how to spend time with their relative in the home, cognitive and physical decline, driving distances, and outside commitments and responsibilities, it would be worthwhile for LTC homes to find ways to foster family relationships both inside and outside of the home.

Despite the limitations of this study, new insight into how family relationships are fostered in LTC has been presented. Physical and cognitive decline significantly impact the fostering of these relationships. A decline in physical and mental health makes it difficult for family members to engage and connect with their relative, even more so when family members are not provided with support that helps them maintain family roles and associated connections. Further research is necessary to increase the ability and capacity of LTC to foster family relationships.

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