The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis and a transition into a long-term care home

By

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Author’s Declaration

I hereby declare that I am the sole author of this master thesis and that I have not used any sources other than those listed in the bibliography and identified as references. I further declare that I have not submitted this thesis at any other institution in order to obtain a degree.

Abstract

Objectives:

This study aimed to explore people living with dementia and family members' meaning of family after a transition into a long-term care home and the construct of family at the family and individual levels. Additionally, this study aimed to explore changes in roles, relationships, and identities within and between families along their dementia journeys.

Methods:

A narrative case study approach was used to present the family stories of each of the four cases featured. The method of analysis used was voice-centred relational analysis (VCRA) which included four readings of the data. The combination of narrative case study approach and VCRA provided a solid foundation to build upon with the sensitizing concepts of roles, relationships, and identities. The narratives and findings utilized quotations from people living with dementia and family members to analyze the sensitizing concepts.

Findings:

From the findings, four main themes emerged, including the *meaning of family, maintaining identity, dementia as a disruptor*, and *dementia as a transformer*. Family meant connection, safety, and love for many of the families featured in this study. Maintaining the identities of people living with dementia through roles, music, and fashion helped maintain their autonomy and dignity. Finally, these themes explored dementia as a disruptor of participants' lives and a transformer of roles, relationships, and identities.

Conclusion:

All of the families featured in this study experienced disruptions and transformations of roles, relationships, and identities after a family member living with dementia moved into a long-term care home. Both positive and negative changes were described, which illustrated that dementia was not always a disruptor towards the negative, but a disruptor toward something new and transformed. This study emphasized the complexity and importance of family relationships.

Dedication

To my two grandmothers, Baba and Paupau.

Your immigrant stories taught me about bravery and perseverance.

Shared laughter over meals showed me joy and happiness.

Your unconditional love showed me what family truly means to me.

You have shaped me into who I am today.

I love you.

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To my participants, thank you for sharing your stories with me. It takes courage to be vulnerable and open, but I am honoured for all of you to have trusted me to share your experiences with me and the world. I hope that I have done your stories justice.

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Contents

Chapter 1: Introduction

1.1 Context

There is a growing population of older adults in Canada, and studies have estimated that there will be over 1 million Canadians living with dementia in the next 15 years (Feldman & Estabrooks, 2017). With increasing diagnoses of dementia in Canada, there have been numerous studies on dementia and social perspectives of living with dementia (Ceci et al., 2018). Dementia is an umbrella term for a progressive condition that includes symptoms such as memory loss, difficulty communicating, impairment of perception, and personality changes (Ashbourne et al., 2021; Evans & Lee, 2014). Studies focusing on the lived experiences of people living with dementia through the exploration of their emotional and subjective experiences are important in helping further our understanding of what it is like to live with dementia (Hellstrom et al., 2005).

The social perspective of dementia research covers the key concepts of roles, relationships, and identity. Past theories that suggested that identity is dynamic and constantly evolving are highly applicable to dementia research because of the changing cognitive abilities of people living with dementia (Klosinka & Leszko, 2023; Kontos, 2004). However, previous research neglected the idea that people living with dementia have a sense of self because they claimed that people experiencing memory loss have an impaired narrative identity (Batra et al., 2016; Klosinka & Leszko, 2023). This perpetuates harmful stigmas that people living with dementia do not have a sense of self-identity. This study explored the concept of the roles, relationships, and identity in people living with dementia and their family members and how it transformed over their dementia journey.

There has been little research regarding the relationships between the family as a unit and people living with dementia (Smith et al., 2022; Roberto & Savla, 2022). The meaning of family and the relationships between individuals differ among family members. Relationships are multi-dimensional and can influence the progression of dementia and individual well-being (Hellstrom et al., 2005; Sharma, 2013; Thomas et al., 2017; van Corven et al., 2022). Past research has focused on dyads in dementia care (i.e. people living with dementia and their spouse, adult children, or grandchildren), which has caused the family unit to be overlooked (Roberto & Savla, 2022). The investigation of the family as a whole unit in this study provided narratives from a variety of perspectives, which painted a picture of the family story.

Transitioning into a long-term care home can be a difficult stage in the dementia journey for many families. Feelings of loss and guilt were often associated with moving a person living with dementia into a long-term care home (Ashbourne et al., 2021). There have been discussions about the changing roles of family members when they are no longer living with the person living with dementia in the community (Konietzny et al., 2018). Additionally, the person living with dementia's sense of identity is often maintained through relationships with family members (Hellstrom et al., 2005; Hellstrom et al., 2007). Moving into a long-term care home can cause changes in people's sense of identity because of the distance from family members and the changes in roles when living outside of the home. The changes in roles, relationships, and identity when the person living with dementia no longer lives with family have not been researched in-depth, especially by including people living with dementia and family members as participants.

There has been little research regarding relationships between family members and people living with dementia, particularly in long-term care homes (Smith et al., 2022; Roberto & Savla, 2022). Dementia research often looked at two individuals: the person living with dementia and the informal care partner (Sinclair et al., 2018). This continued to produce similar data findings and reproduced analogous dichotomies (Sinclair et al., 2018). Previous research focused on dyads in dementia care, including the person living with dementia and spouses, adult children, or grandchildren, but rarely studied the family as a unit. Additionally, any family members who were not considered the informal care partner were often grouped with “extended family members” or “others,” which often obscured the heterogeneity of families (Roberto & Savla, 2022). Grouping family members together in one category in research does not accurately represent the relationships among individuals, which was why I chose to look at named family members in relation to the person living with dementia and looked at families as a whole unit. Although there has been research with people living with dementia on maintaining a sense of self through relationships, few studies focus on the nature of relationships and the experiences of both people living with dementia and their families (Hellstrom et al., 2007). This study expanded on the scarce literature on the sense of self and the meaning of family within the family unit with dementia in the picture.

1.2 Purpose of the Study

The purpose of this study was to explore what family means to families experiencing a dementia diagnosis, particularly once a family member has moved into a long-term care home. It was important to tell the stories of people living with dementia and their families to share their experiences and provide a rich understanding of family relationships and the meaning of family with dementia in the picture. Few studies addressed the family as a unit in dementia research, and this study’s primary focus on the family experiences of dementia was unique in this area of research. Additionally, there was scarce literature looking at the changes in roles, relationships, and identities in people living with dementia and their families. Using a narrative case study approach, this study explored what family meant to people living with dementia and their families at this point in their dementia journey. I aimed to explore the construct of family at a family level (i.e. the group level) and at the individual level (i.e. the person living with dementia and their family members).

1.3 Research Questions

The research questions were:

1) How do people living with dementia and family members describe their family?
2) Who is considered family and why?
3) What does family mean to people living with dementia and their families?
4) Have personal identities, roles, and relationships changed since the dementia diagnosis and admission to a long-term care home? If so, how and why?
5) Has the family identity changed since the dementia diagnosis and admission to a long-term care home? If so, how and why?

1.4 Significance of the Study

This study explored how living with a dementia diagnosis and the transition into a long-term care home impacted the roles, relationships, and identities of people living with dementia and their families. By bringing attention to the effect of a dementia diagnosis on the individual and the broader level of families, participants were able to describe their family's experiences with dementia. With the emphasis on family relationships, this study showed the importance of family research by looking at the family unit, not just dyads in care. The findings of this study added to the body of literature about relationships between people living with dementia and their families. By looking at roles, relationships, and identities within a family setting, this study shared the experiences of families and challenged the narrow, dyadic relationships often seen in dementia research.

This study highlighted the roles, relationships, and identities of people living with dementia and their families after a dementia diagnosis. The concept of the self and identity, and how people have changed through shifts in roles and relationships, was explored. The sensitizing concepts within this study included roles, relationships, and identity and how they contributed to a sense of self and personhood.

A long-term aim of this study was to combat the stigma surrounding people living with dementia in aspects such as personhood, identity, and selfhood. Treating every individual with dignity and respect, regardless of their diagnosis, is a human right that can be easily afforded to everyone. I am closely affiliated with people living with dementia through my work and research. It was important to myself and the members of my committee to provide a safe place for people living with dementia to express themselves and to be afforded their human rights.

Another long-term aim of this study was to include inclusive and positive language in all areas of the research process (i.e. proposal, data collection, data analysis, final thesis, and dissemination of findings). A quote by Kontos (2004) highlighted the frustratingly negative literature on dementia and said, "The disparate and discursive literature on [Alzheimer's disease] and other dementias reads as a catalogue of horrors and documents of fear, dread, and loss" (p. 845). The focus on loss, burden, and grief in previous research perpetuated negative perspectives on dementia and dementia care (Hellstrom et al., 2007). Research has the power to change societal views on dementia and to focus on living *well* with dementia. There are other aspects to dementia that are not centred on loss, such as loving relationships with family and deep friendships with neighbours and community groups. Highlighting positive experiences and sharing the stories of people living with dementia and their families can add to the literature that is often focused on negative aspects of dementia.

Chapter 2: Literature Review

2.1 Dementia

Currently, more Canadians are living longer and, as a result, we are seeing a large demographic shift in the aging population (Feldman & Estabrooks, 2017). With the population increase of seniors, there has been an increasing demand for healthcare, especially within long-term care homes for people living with dementia (La Fontaine & Oyebode, 2014). Studies have shown that 50 million people were diagnosed with dementia worldwide in 2018 (Grundberg et al., 2021). Over 1 million Canadians are projected to be living with dementia by 2038, and over 152 million people living with dementia worldwide by 2050 (Feldman & Estabrooks, 2017; Grundberg et al., 2021).

Dementia is an umbrella term for a group of symptoms associated with a progressive decline in cognition (Ashbourne et al., 2021). These symptoms often include memory loss, difficulty communicating, impairment of perception, and personality changes (Ashbourne et al., 2021; Evans & Lee, 2014). Dementia is not a natural sign of aging, despite the beliefs of many non-Western cultures (Jacklin & Walker, 2019). Some cultures go so far as to say that dementia is a “White people's disease,” but people from any race or ethnicity can experience dementia (Jacklin & Walker, 2019). Dementia is a progressive condition, and people living with dementia often need assistance (i.e. bathing, dressing, cooking, cleaning, eating, etc.) as they continue in their dementia journey (Evans & Lee, 2014). Some people living with dementia and their informal care partners may recruit family members, friends, or medical professionals to assist in the care of a person living with dementia. Assisting in the care of a person living with dementia may also include connecting with community resources for respite care or connecting with long-term care homes when community living is no longer an option for the person living with dementia and their family.

People living with dementia face unique challenges with their diagnosis, not just from a biomedical perspective, but from a social perspective (Ceci et al., 2018; Evans & Lee, 2014). The biomedical perspective involves methods and units of analysis that are focused on the biological and medical impact of dementia, whereas the social perspective focuses on the experience of living with dementia in everyday life (Ceci et al., 2018). In past research, dementia has been researched using the biomedical perspective, which mainly provided suggestions for managing symptoms through pharmaceutical intervention (Batra et al., 2016; Hellstrom et al., 2005). The biomedical perspective in intervention medicine is important in illustrating disease models of dementia (Ceci et al., 2018); however, it disregards the perspectives of real people in the real world. The shift towards a model of dementia research that focuses on emotional and subjective experiences helps increase our understanding of the lived experiences of people living with dementia (Hellstrom et al., 2005).

Some of the social challenges of living with dementia include stigma, discrimination, and social isolation (Sun et al., 2022; Birt et al., 2019). Stigma is a set of negative beliefs that are unfairly put on an idea or group of people (Merriam-Webster, 2024). There has been a negative stigma around dementia by society that has resulted in the discrimination of people living with dementia. This has caused many people living with dementia to distance themselves from others because they are afraid that sharing their diagnosis will cause them to be objectified and stigmatized (Birt et al., 2019; Shannon et al., 2018). This can lead to an increase in social isolation for people living with dementia (Birt et al., 2019; Shannon et al., 2018). Additionally, some studies suggested that people living with dementia do not maintain their identities or their perceptions of the self (Kontos, 2004). This perpetuates the stigma that people living with dementia are not able to interact or participate in society in a meaningful way. This is false because people living with dementia are aware, engaged, and constantly interacting with the world in their own ways. People living with dementia continue to have their identity and perceptions of the self, regardless of cognitive changes. Challenging the stigma around dementia is especially difficult when the public does not understand what dementia is or what the person living with dementia is capable of. That is why it is important to educate the public on dementia and show them that living well with dementia is possible (Phinney et al., 2023). People living with dementia, their families, care partners, researchers, and leaders in the community all play key roles in challenging the stigma about dementia.

2.2 Identity, Roles, and Relationships

Previous researchers have explored the concept of identity and how it is tightly intertwined with the concepts of roles, relationships, and the self. Identity and the self are complex topics with differing definitions among researchers. Terms such as identity, personhood, self, and selfhood are often incorrectly used interchangeably in research (Norberg, 2019). Simply put, identity is defined as how one perceives how they are viewed by others, whereas the self is how one views themselves. There are varying definitions of the self, some of which include:

1) The self refers to the total person through the use of language (i.e. the use of "I" or "me") (Leary & Tangney, 2003).
2) The self as an individual's personality, beliefs, and values (Leary & Tangney, 2003).
3) The self is constructed from our interactions and communication with others (Gubrium & Holstein, 2001).

4) The self as a construction from the individual’s world views and their personal agency (Sabat & Harré, 1992).

A particularly fitting definition of the self was highlighted by Cohen-Mansfield and colleagues in their discussion of people living with dementia and their reflections of the self. Cohen-Mansfield (2000) said that the self could be defined as the “… roles, identities, attributes and preferences which an individual attributes to [themselves], and which therefore reflect selfhood” (pg. 383). This definition is highly applicable to people living with dementia because of its broad description of how the self can be reflected upon.

A useful definition for identity was used by Klosinka and Leszko (2023) and described identity as “a fluid, fragmentary, contingent, and discursively constituted construct of selfhood rather than a static and finished entity.” This definition expands on how selfhood and identity are intertwined and variable; however, they are not the same concept. Klosinka and Leszko (2023) further explained that identity is formed through language, social habits, socioeconomic class, gender, and age. The layered definitions of identity help paint a picture of identity as multifaceted and dynamic. There are differences and similarities between the self and identity. The self is an internalized reflection that is unique to every individual and is shaped by an individual’s roles and attributes, whereas identity is an externalized reflection that is constructed by other people. The self is constructed by the individual, whereas identity is relational and can be constructed by a group or by an individual. Every individual is different: while some individuals may have a strong connection between the self and identity, others may have a disconnect between the self and identity.

Expanding on the self and identity is the idea of personhood. In research, there is an understanding that the self, identity, and personhood are influenced by the social environment individuals are exposed to. Kitwood defined personhood as "… a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (1997, p. 8). Additionally, the self is developed and maintained by the social relationships we have with others. These definitions of personhood and the self explain that they are somewhat dependent on the relationships with others. I found these definitions rather problematic because they lead one to believe that people who are socially isolated or have challenging relationships with others have less personhood than people who do not experience social isolation. The idea that the self and personhood are dependent on the relationships people have with others and are given to people by their social circles is limiting to their autonomy. The concepts of the self, identity, and personhood are important to consider in family research because family relationships can greatly impact these concepts by reinforcing a person living with dementia's sense of self and continuing to maintain their feelings of personhood (Hellstrom et al., 2005; Hellstrom et al., 2007). The connections we have with our families are what shape our perceptions of the self, which is why this study explored family relationships and how roles, relationships, and identity have been impacted by a dementia diagnosis and a move into a long-term care home.

Interestingly, a question posed in a paper by Kontos (2004) was "Do we cease to be persons when we lose our memory?" This question was asked by a physician at the University of California who described the self as deeply connected to memory and cognitive abilities (Kontos, 2004). Kontos went on to challenge the idea that the self is dependent on memory and cognition by illustrating in an ethnographic study that people living with dementia were aware, engaged, and constantly interacting with the world in their own ways. The self persisted regardless of cognitive ability (Kontos, 2004), although it did adapt to a change in different settings.

Contrasting previous definitions of the self, Wiersma and Dupuis (2010) described the self as an evolving and ever-changing concept. The self is constantly being constructed and reconstructed as we interact with the world (Wiersma & Dupuis, 2010). This definition reflects the growth and development of the self as people experience life. For research involving people living with dementia and their families, this definition is much more appropriate because of the inclusion of change, adaptation and transformation. People experiencing a dementia diagnosis often experience changes in their perceptions of the self and identity. A definition that highlights that the self can be constructed and reconstructed is appropriate to use when conducting research with people living with dementia and their families.

As previously mentioned, dementia research in the past was heavily influenced by biomedical research models (Batra et al., 2016). Although this was helpful in describing dementia progression and symptoms, this was not beneficial in the exploration of sociological experiences of people living with dementia. Previous biomedical models of dementia entirely neglected the idea that people living with dementia had a sense of self and treated people living with dementia "as if they lack 'selves'" (Batra et al., 2016). Additionally, researchers said that narrative identity was often impaired in people experiencing memory loss (Klosinka & Leszko, 2023). This led researchers to believe that people living with dementia lost their sense of self as their ability to retain memories was lost (Klosinka & Leszko, 2023). The idea that people living with dementia do not have a sense of self-identity perpetuates harmful stigmas. Researchers are at the forefront of knowledge and education and have the ability to change the harmful ideations and stigmas surrounding dementia with the language they use in their research. It should be a goal of all researchers to use inclusive and respectful language when discussing the participants of the study, regardless of their abilities.

Maintaining identity as dementia progresses is important for maintaining the dignity, autonomy, and personhood of people living with dementia (Chung et al., 2017). Identity maintenance can be done independently or in joint efforts with family members (Chung et al., 2017). As seen in the literature, some important factors for maintaining identity included stable routines, activities, and relationships (Chung et al., 2017; Cronfalk et al., 2018). Maintaining belonging through continuity in relationships is important to maintaining identity (Cronfalk et al., 2018). Cronfalk and colleagues discussed the importance of maintaining previous activities and habits as they were deeply ingrained in personal identity (2018). This finding suggested that people living with dementia maintained their identities from before their diagnosis, regardless of changes to cognition (Cronfalk et al., 2018). Within the context of this study, I explored how maintaining the identities of people with dementia was important for maintaining the self and personhood, and how family members contributed to maintaining identities.

A role is defined by Cambridge University as "the position or purpose that someone or something has in a situation, organization, society, or relationship" (2025). Some examples of roles within the context of family in this study included spouse, parent, child, grandchild, grandparent, care partner, cousin, and friend. Other roles included leader, student, teacher, homemaker, and immigrant. Roles are what make up someone's unique identity. Roles are important in dementia research because they illustrate that the person living with dementia's unique self is shaped by how they engage and interact with the world (Kontos, 2004). Roles within a family unit are important in dementia research because they reveal the responsibilities, expectations, and interactions among family members. This study examined the roles of people living with dementia and their family members and how roles shape individual and family identities.

Some people may define relationships as romantic, platonic, or familial. Other people may define relationships as a connection between people, like family members, friends, co-workers, or other people in their lives. Relationships can be positive or negative, or they can be close or distant. Relationships can change and evolve over time. This study explored relationships among people living with dementia, their blood-related family members, and those whom they deemed family regardless of blood relation. It explored positive and negative relationships, close and distant relationships, and changing relationships of people living with dementia and their families.

Roles and relationships contribute to identity because of their interconnectedness and influence on one another. Roles established through organizations, institutions, and society contribute to people's position and purpose. This contributes to identity because roles are often externally seen and enforced by other people. Relationships among individuals and groups contribute to identity for the same reason: identity is enforced by other people, and relationships are key to identity construction. This study examined the connections between roles, relationships, and identity among participants at the individual and group level.

Past studies exploring the concepts of roles, relationships, and identities were primarily qualitative because a quantitative model did not thoroughly explore the in-depth and deeply personal ideas that these concepts required during analysis (Baird et al., 2018; Daniels et al., 2007). Similarly, this study examined these concepts using qualitative case study methods. These concepts were best explored through detailed narratives of the family story and analysis using voice-centred relational approach. Storytelling through the family narratives provided context for the development of roles, relationships, and identities, and provided a backstory for these concepts and their transformations.

2.3 Who is a Caregiver?

Although this study was about family, it was important to define frequently used terminology when discussing care. The term “caregiver” can refer to family members or paid professionals who look after a person living with dementia. Furthermore, a primary caregiver is the main person providing care for a person living with dementia. There are various responsibilities for caregivers, ranging from instrumental care (i.e. arranging medical appointments) to personal care (i.e. bathing, feeding, etc.) and other responsibilities that are specific to their role. In recent years, the term “care partner” has been used to replace caregiver. Caregiver expresses that the individual is “giving” something to the person in need of care, whereas care partner conveys the idea that people are working together in a reciprocal relationship (Jacobsen, 2022). There have been discussions that “caregiver” is a term that describes the burden associated with caring for an individual, but this is not always the case. Many people caring for a family member found caring rewarding and said caring contributed to the reciprocal relationships they built over time (Thomas et al., 2017). In order to view care relationships in a more positive light and support the dignity of people living with dementia (Jacobsen, 2022), the term “care partner” was used in this study.

A term used to separate professional from non-professional care partners is the term “informal care partner.” Informal care partners of people living with dementia are care partners who do not have formal or professional experience within the healthcare field. This can include family members, friends, neighbours, and others who are not health professionals. The term “informal” does not intend to diminish the work required in caring for people living with dementia. Some care partners have expressed that the term “informal care partner” overlooks the genuine relationships among family members and friends. Not all family members relate to the term care partner, and not all care partners are family members. Using language like "family member" highlights the relationship between the person living with dementia and their family members instead of calling people caregivers or care partners. This study focused on family members as defined by people living with dementia.

2.4 Defining Family

It is agreed upon by much of the literature that family relationships influence the progression of dementia and overall well-being (Sharma, 2013; Thomas et al., 2017; van Corven et al., 2022). Family relationships are distinct, complex, and of varying meaning between families (Thomas et al., 2017). In dementia research, there has been limited work researching the "multi-dimensional and dynamic inter-relationships" among people living with dementia and their families (Hellstrom et al., 2005, p. 8). Some studies have defined family as people living in a single household, while others have said that a family consisted of "two or more people united by marriage, blood, adoptions, or consensual union in a single household" (Sharma, 2013). Other studies described the "modern family," which was more inclusive and included single parents, grandparents, grandchildren, step-parents, and step-siblings (Perion et al., 2021).

Additionally, family models in past research have been heavily influenced by heteronormative and societal beliefs. For example, families were previously described as a heterosexual couple and their children (Roberto & Savla, 2022). This does not encompass the modern definitions of family where people may be unmarried, living in multiple households, living with non-family members, and other unique situations (Roberto & Savla, 2022). Moreover, studies on dementia that looked at family relationships typically combined family members into a category they often called "extended family" (Roberto & Savla, 2022). This reduced the individual experiences of adult children, grandchildren, siblings, and other family members into the experiences of the "extended family" instead of sharing the unique, dynamic experiences in each relationship. This study focused on the individual and collective experiences of all members of the family unit and explored the dynamic relationships of the family.

Researchers impose a definition of family, so there are complexities that external definitions cannot capture. The varying descriptions of family, as discussed previously, and what constituted a family member, illustrated that the definition of family differed among individuals. In the context of dementia, the definition of family by Sharma (2013) would exclude people living with dementia who do not reside in the home and live in a long-term care home or palliative care facility. Using Sharma's definition, these people would not be considered family. Furthermore, part of the purpose of this study was to explore what family meant to people living with dementia and their family members.

There is plenty of research available on happiness, life satisfaction, quality of life, and other measures of well-being, but there is very little research available focusing on complex relationships and diverse family structures with dementia in the picture (Thomas et al., 2017). Illustrating the relationships between family members can provide perspectives on the social resources and connections available to a person living with dementia and the people within their family (Thomas et al., 2017). This study explored the experiences of people living with dementia and their families during their dementia journey, and how family structures and relationships have been shaped because of the diagnosis.

2.5 Family Relationships

In European countries, 66% to 94% of people living with dementia live at home in the community where family members are the informal care partners (Grundberg et al., 2021). In Canada, more than half of Canadians living with dementia are living at home with family and community support (Ceci et al., 2019). There are policies in Canada that encourage families to take care of their family members for as long as possible before institutionalization (Ceci et al., 2018). However, these policies are not always effective (Ceci et al., 2018). Balancing a career, childcare, and managing their own health problems in addition to providing care for a person living with dementia can be very challenging and sometimes a source of stress for families (Barken, 2017). Some family members said that they had to change their careers, move their families closer to their older family members, and move their children to closer schools in order to take care of their older family members (Jacklin & Walker, 2019). There are physical and mental challenges associated with taking care of a person living with dementia, including difficulties with their physical health, like falls and mobility, and psychological symptoms (Zhou et al., 2023). These challenges can impact both the quality of life for the family members and the person living with dementia and can lead to a transition into a long-term care home (Zhou et al., 2023).

2.5.1 Changing relationships

A dementia diagnosis not only impacts the person living with dementia but also impacts the family members close to them. Dementia diagnoses often have an impact on family relationships and can influence the health and well-being of other family members (Busted et al., 2019; Thomas et al., 2017). Caring in the community or in a long-term care home for a person living with dementia can be both rewarding and challenging for family members. There have been reports of conflicts between family members about finances, rivalries, and deciding what was best for the person living with dementia (Busted et al., 2019; Smith et al., 2022). Challenges can arise among family members when there are important decisions to make for the person living with dementia after a move into a long-term care home, and family members want to make a decision that reflects what the person living with dementia would have decided for themselves (Busted et al., 2019).

2.5.2 Adult children

Some studies demonstrated that many older adults felt like they could rely on their family members to take care of them as they aged in the community (Barken, 2017). However, not all people living with dementia had family members nearby to take care of them (Herron & Rosenberg, 2017). The absence of supportive family members in caring for a person living with dementia was a challenge for the informal care partner (Herron & Rosenberg, 2017). For example, some adult children did not reside in the same city as their parent with dementia (Herron & Rosenberg, 2017). This was challenging when they needed to provide aid for a parent with dementia. In a study by Egdell (2013), one participant said that they had become the main informal care partner of their parent with dementia because their sibling lived in another city. Although some siblings lived too far away to aid the parent, they sometimes provided financial support (Smith et al., 2022). While financial support was helpful to some degree, the physical care of the parent was often the major issue for the sibling in care (Smith et al., 2022).

Relationships among individuals involved in the care of a person living with dementia are important in providing quality care in long-term care homes. The dynamic between friends and family members can greatly influence the well-being of all individuals involved (van Corven et al., 2022). There were various studies that demonstrated contrasting research about past and current relationships among people living with dementia and their family members. Some studies showed that family history among parents and their adult children influenced the caregiving interactions that were seen after a dementia diagnosis at home in the community (Chen et al., 2017; Venters & Jones, 2020). If problematic behaviours were exhibited in the relationship prior to a diagnosis, there are often complications in caregiving after the diagnosis of dementia (Chen et al., 2017; Kokorelias et al., 2022). Similarly, close relationships between parents and adult children prior to a diagnosis resulted in increased positive relationships and continued communication after a diagnosis (Kokorelias et al., 2022; Venters & Jones, 2020). In contrast, some studies have illustrated that closer relationships pre-diagnosis led to greater deterioration of relationships post-diagnosis because of decreases in engagement and less emotional closeness between family members (Venters & Jones, 2020). Other research demonstrated that caring for a family member with dementia created more meaningful relationships regardless of previous relationship status (Perion et al., 2021). The contrasting research on how previous family relationships impact caring is important in highlighting that every family story is different.

2.5.3 Sibling relationships

Studies focused on mixed gender sibling dyads found that there were more contributions by sisters than by brothers in the care of a parent living with dementia (Kokorelias et al., 2022). Gender, personality, and skillset each contributed to task delegation within the family (Kokorelias et al., 2022; Smith et al., 2022). While male adult children often took care of the finances and laborious household work, female adult children contributed to the personal and emotional care of the family member (Kokorelias et al., 2022; Smith et al., 2022). Although sons helped in the care of the parent, the responsibilities of task delegation and organization often landed on the daughter's shoulders (Kokorelias et al., 2022). This caused resentment and conflict due to the feelings of unequal contribution in caretaking responsibilities (Kokorelias et al., 2022). Sibling pairs who shared common goals and divided tasks equitably were more likely to be satisfied in caring for a parent with dementia (Kokorelias et al., 2022; Smith et al., 2022). Many sibling pairs found that fairness in sharing the care load bought them closer together (Smith et al., 2022). Similarly to relationships between parents and adult children, a good relationship between siblings before caretaking benefited the pair after the diagnosis (Kokorelias et al., 2022).

Sibling dynamics shifted with the responsibility of caring for a parent living with dementia. Some siblings were left to care for their parent living with dementia because of their employment situation, like being laid off, a volunteer, or retired (Egdell, 2013). In Egdell’s (2013) study, a participant who had been off work due to an illness was thrust into caring for a parent living with dementia. The participant explained how caring for a parent was difficult and unpaid, whereas their sibling could not care for the parent because of their paid employment (Egdell, 2013). In contrast, Grigorovich and colleagues (2016) discussed sons caring for a parent living with dementia and explored how the sons established boundaries in care, including limiting the type of care they provided and the time they spent providing care. The dynamics between siblings in responsibilities, employment, and financial compensation for the work they were completing differed between families.

Shared care responsibilities were often influenced by sibling dynamics and previous sibling relationships. The literature has explored sibling dynamics in care and how these dynamics either benefitted the family and grew stronger, or impacted familial relationships detrimentally (McDonnell et al., 2013). Siblings expressed frustration with their siblings because their siblings were not doing enough to care for their parent living with dementia (McDonnell et al., 2013). In a study by Egdell (2013), a participant felt hurt by their lack of support from their sibling who lived far away, but they were resigned to the fact that they could not do anything about the relationship. This illustrated the tension and resignation some siblings felt when they believed that the care responsibilities between siblings were unequal. In other families, some siblings delegated responsibilities like emotional support, personal care, and care management among siblings (Grigorovich et al., 2013). In one study, daughters and women often took on the emotional support and personal care responsibilities, while sons and men took on the role of care manager (Grigorovich et al., 2013). This study explored family relationships and provided context on past and present family relationships through family narratives.

2.5.4 Intergenerational relationships

Dementia does not only impact the lives of adults. Children and grandchildren can be affected by the changes in adults close to them and, in some cases, be involved in the care of a person living with dementia (Chirico et al., 2021; Perion et al., 2021). The transition between the dependent nature of childhood to the independence of adulthood can be challenging when a young person is also caring for a parent or grandparent living with dementia (Grundberg et al., 2021). Some studies have recommended that young carers be labeled as "vulnerable youth" due to the levels of burden and stress experienced at a young age (Grundberg et al., 2021). Although there are positive aspects of caregiving at a young age, like feelings of mastery, self-worth, and empathy, there are also many negative aspects as well (Chirico et al., 2021). Studies suggested that caring as a young person led to more psychological impairment and damage, stress, and hardship than what was experienced by older carers (Chirico et al., 2021; Roberto & Savla, 2022).

Children involved in the care of a family member with dementia at home often felt like they had strains on their choices for careers, education, dating and relationships, and social lives (Chirico et al., 2021; Roberto & Savla, 2022). The roles and responsibilities assigned to children at a young age in caring for a parent with dementia and the mental and emotional well-being of the well-parent were challenging for children to navigate (Chirico et al., 2021). This "role reversal" of care was where the child cared for the parent by taking on what would normally be a parental responsibility (Grundberg et al., 2021). Responsibilities such as domestic tasks, finances, medications, and emotional support were just some examples of tasks given to children involved in the care of their family member with dementia (Grundberg et al., 2021). These roles were often thrust upon the children as one teenager said, “I really became the man of the house. At 15/16 years old, that was kinda rough” (Grundberg et al., 2021).

Children have struggled with having the parent with dementia physically close to them, but emotionally and psychologically absent (Chirico et al., 2021; Roberto & Savla, 2022; Grundberg et al., 2021). This has been termed “ambiguous loss” and can be especially challenging for young children to understand (Grundberg et al., 2021). Children have also expressed that their parent missed important milestones and there are feelings of grief in seeing their parent’s decline in health (Chirico et al., 2021). Although there are emotional and psychological changes in the progression of dementia, this does not contribute to “loss” of the sense of self. People living with dementia continue to have a sense of self regardless of the stage of dementia (Smebye & Kirkevold, 2013).

Family relationships between generations can benefit older and younger generations (Thomas et al., 2017). In a study by Perion, a child discussed their experience helping their grandparent with dementia and said, “It always feels good helping someone that needs help” (Perion et al., 2021). Positive intergenerational relationships among grandparents, adult children, and grandchildren have been known to increase feelings of social support, social connection, emotional support, self-esteem, and result in positive mental health outcomes (Perion et al., 2021; Thomas et al., 2017). Research showed that having positive relationships with family members promoted healthier behaviours and promoted closeness and meaning in relationships (Thomas et al., 2017). Researchers described the relationships among children and family members with dementia as “bi-directional” because of the reciprocal affection between generations (Perion et al., 2021). When discussing their relationship with their grandfather, a child said, “just because he doesn’t remember does not mean he doesn’t care” (Perion et al., 2021). This highlighted the bi-directional relationships among children and their grandparents with dementia. Close relationships among grandparents and grandchildren can be very rewarding for both groups, as well as add meaning and purpose to both parties’ lives (Thomas et al., 2017).

2.5.5 Spousal relationships

In spousal relationships maintaining connection through intimacy, whether physical, emotional, or intellectual, often decreased as dementia progressed (Eskola et al., 2022; Evans & Lee, 2014). These changes caused sadness, frustration, and guilt in both partners because of the changing abilities of the person living with dementia (Eskola et al., 2022). A study by Evans and Lee (2014) discussed that there were changes to marital relationships and marital communication as dementia progressed. Some individuals in the study described the changes from partner to carer and from independence to dependence (Evans & Lee, 2014). There was a fluidity of roles and responsibilities between partners as the well-partner took on roles that were not their responsibility earlier in the marital relationship (Evans & Lee, 2014). This change in roles can be challenging in regard to feelings of identity as a spouse, a member of the household, and an informal care partner. This study looked at family as a whole and the changing roles that accompanied the progression of dementia.

Another challenge for many couples was the ability to be intimate and affectionate with one another as dementia progressed. There were challenges in reciprocity of intimacy in couples and the responsibility to maintain levels of intimacy often landed on the spouse (Eskola et al., 2022). Spouses have expressed feelings of loneliness in couplehood despite having their partner with them (Eskola et al., 2022; Evans & Lee, 2014). This was deemed “unmarried-marrieds” which meant that there was a physical presence, but a cognitive absence of the partner living with dementia within the couple (Evans & Lee, 2014). Hellstrom and colleagues (2007) discussed that couplehood was about the “we” in a relationship and discussed the loss of couplehood as the increasing use of “I”. Couples reported a decrease in physical intimacy with each other; however, they said that there was an increase in emotional intimacy (Evans & Lee, 2014). Despite the noted decrease in physical intimacy, some couples expressed the ability to be physically intimate with each other by completing tasks together, holding hands, or hugging as simple ways they maintained connection (Eskola et al., 2022). They emphasized that maintaining the relationship was not all about physical intimacy, but through mutual respect, caring, and thoughtfulness (Evans & Lee, 2014). It is worth noting that many of the studies about relationships with a person living with dementia took place within the community and did not look at relationships among those who had moved into a long-term care home (Evans & Lee, 2014).

2.5.6 Connection and identity

With the changing abilities of the person living with dementia there were often changes in the relationship quality and the quality of interactions between the person living with dementia and their families (van Corven et al., 2022). “Relationship quality” and “quality of interactions” referred to meaningful relationships and engaging interactions with someone. Changes to the relationships and interactions among family members and people living with dementia impacted feelings of connection and engagement (van Corven et al., 2022). Generating meaningful connections with people living with dementia through activities, story telling, and purposive tasks helped both parties feel engaged (van Corven et al., 2022). People living with dementia expressed that their families often tried to protect and shield them from potentially difficult social situations (Birt et al., 2019). This resulted in the person living with dementia experiencing feelings of reduced agency (Birt et al., 2019). They felt like they were being treated like children, being controlled, and losing their sense of self (Birt et al., 2019). These feelings of spoiled identity were difficult for people living with dementia to deal with, especially when the people close to them were contributing to these feelings (Birt et al., 2019).

The relationships between a person living with dementia and their family members substantially contributed to the person living with dementia's sense of self and helped maintain their personhood (Hellstrom et al., 2005; Hellstrom et al., 2007). Family members were key contributors to sustaining self-esteem, sense of agency, and personhood for people living with dementia (Hellstrom et al., 2005; Hellstrom et al., 2007). Sharing tasks and involving people living with dementia in decision-making were just some ways families helped maintain a person living with dementia's sense of self (Hellstrom et al., 2007). As discussed previously, a sense of self and personhood are closely linked to the relationships people have with others (Hellstrom et al., 2005). The connections people have with those close to them shape their perceptions of the self, which is why this study looked at the relationships between family members and perceptions of identity.

Previous studies have looked at dyad relationships in dementia, such as the person living with dementia and their adult child, their spouse, or their grandchildren (Sinclair et al., 2018). However, very few studies have looked at the relationships among multiple family members and a person living with dementia. This study used qualitative methods to explore the meaning of family to people living with dementia and their family members. Through the exploration of roles, relationships, and identities after a transition into a long-term care home, new knowledge about unique and dynamic family relationships were constructed.

2.6 Transitioning into a Long-Term Care Home

As the stages in the dementia journey progress, many people living with dementia and their families arrange for alternative care options, including a long-term care home and palliative care options (Ashbourne et al., 2021). Healthcare transitions are transition periods where a person moves from living at home in the community to a long-term care home or another transition location (Ashbourne et al., 2021). Institutionalization is often due to changes in the person living with dementia's cognitive, physical, behavioural, or psychological functioning (Ceci et al., 2018). These changes are noted by professionals or addressed in the event of a crisis where the informal care partner is no longer able to care for the person living with dementia alone (Ceci et al., 2018).

These transitions can be difficult for the person living with dementia and their family. It has been described as a stressful experience by families, both for the person moving into a different type of care and for the people assisting the move (Ashbourne et al., 2021). Families have expressed that they felt lost after moving the person living with dementia into a long-term care home (Ashbourne et al., 2021). They struggled with doing things alone and had to move into a new role of learning (Ashbourne et al., 2021). Families have expressed stress and guilt as they witnessed the progression of dementia in their family members (Konietzny et al., 2018). They often felt a sense of duty to the person living with dementia and took on more roles as the person living with dementia changed (Konietzny et al., 2018). Many family members continued to advocate for the person living with dementia after the transition into a long-term care home

(Konietzny et al., 2018). This helped to maintain the person living with dementia's sense of self and personhood as a member of the family despite no longer living at home.

Other qualitative studies have illustrated the difficulties families face when moving a family member with dementia into a long-term care home. In a study by Duggleby and colleagues (2013), families expressed their despair when they were not able to connect with their family members, either through verbal, physical, or emotional connection. Studies on spousal care partners have illustrated changing roles and identities that are tied to moving a spouse into a long-term care home (Mullin et al., 2013). Although the physical separation of the person living with dementia and their spouse has been studied, the separation between a person living with dementia and their family after a transition into a long-term care home has not been extensively studied (Mullin et al., 2013). There have been no studies found in my literature search that examine the family as a unit. Research highlighting the relationships after a transition into a long-term care home would add to the body of literature surrounding the experiences of people living with dementia and their families. This study explored the relationships among people living with dementia and their families after a transition into a long-term care home, including how roles, relationships, and identities were affected after the transition.

Family relationships are extremely variable and complex. Exploring family stories through the incorporation of roles, relationships, and identity as sensitizing concepts in the dementia context illustrated the meaning of family and family identities both at the individual and group levels. The exploration of the family as a unit through qualitative methods contrasted the primarily dyadic approach to dementia research and shared the family story through the lens of multiple family members. The investigation into family relationships with dementia in the picture and the changes in roles, relationships, and identity contributed valuable information to dementia research, especially when explored through a narrative case study approach to gain perspectives from those living with dementia and their families.

Chapter 3: Methodology and Conceptual Framework

Dementia research often uses grounded theory, phenomenology, or case study approaches to study the experiences of people living with dementia (Hellstrom & Torres, 2016). This study used a case study approach to explore the experiences of families with dementia in the picture. Case study approach is a method of "… [investigating] a contemporary phenomenon within its real-life context" (Yin, 2003). This method helps understand complex phenomena, but within a specific time and context (Yin, 2003). Case studies are able to retain characteristics from people's stories in ways that other approaches are unable to (Yin, 2003). This study provided in-depth narratives that add to family research on dementia. Case study approach has been used in dementia and family research in the past and continues to provide unique data in the field of research.

The case study methodology within this study allowed researchers to explore the participants' experiences by focusing on a single family for each case. This study featured four families; therefore, four cases were explored. This collective case study approach presented multiple cases within one study. This method provided unique details and showcased various perspectives from people living with dementia and their families.

In this study, I extended the case study approach to incorporate a narrative method. The narrative method of presenting the study's findings told the personal stories of each family in an impactful, truthful, and creative way. Narrative approaches are commonly used in case study research because of its in-depth engagement with the participant's story (Daniels et al., 2007). An interpretation and narration of the story was built from the relationship between researcher and participant, which resulted in "unique and rich data" (Daniels et al., 2007). In this study, each family was featured in their distinct family narrative. Their stories were analyzed and compared to the other families in the findings section of the study.

Storytelling is an effective way to illustrate how people view themselves, their relationships, and how they fit within a group. People create themselves through stories by using language to reflect how they think of themselves. Stories offer insight into perceptions of the self through the use of language. Within this study, stories offered a unique perspective on perceptions of the self, as well as family dynamics and narratives. Storytelling in previous qualitative studies involving people living with dementia showed that people living with dementia were able to share personal narratives, particularly in response to generic pictures of major holidays as prompts (Fels et al., 2011). This illustrated that people living with dementia were completely capable of responding to pictures with personal narratives of their experiences (Fels et al., 2011). Fels and colleagues (2011) also suggested that further research should consider the use of pictures to engage people living with dementia in conversation about their life stories. This study used family pictures as prompts for people living with dementia and their family members to engage in conversations about family stories and the meaning of family.

Previous dementia and family research focused on dyads in care, including the person living with dementia and their main informal care partner. The exploration of the entire family unit with the use of a case study approach painted a larger, more detailed picture of living with dementia. Concepts such as the self, identity, and personhood have been explored in dementia research, especially within the context of relationships (Hellstrom et al., 2005; Hellstrom et al., 2007; Kitwood, 1997; Klosinka & Leszko, 2023; Kontos, 2004). This research has been limited to the person living with dementia and their main informal care partner (Hellstrom et al., 2005).

Furthermore, there is limited research conducted about the self, roles, and identity by exploring the relationships among people living with dementia and their families (Hellstrom et al., 2007). This study focused on the connection between three sensitizing concepts: roles, relationships, and identity. As previously mentioned, these concepts are closely related to the self and personhood in the social science field. The connection between these concepts and how they contributed to the self and personhood with dementia in the picture was explored in this family research study.

The experiences of participants and their descriptions of family, relationships, and their perceptions of roles and identity were presented using the narrative case study approach because of its detailed and illustrative method of telling the family story. Narrating the family story through this approach shared the personal stories of the participants in a meaningful way. Additionally, presenting each family story provided important context on which to build upon when addressing the sensitizing concepts of roles, relationships, and identities.

Chapter 4: Methods

4.1 Study Design

Using a case study qualitative approach, this study explored the experiences of people living with dementia and their families and how roles, relationships, and identities have changed while living with dementia. Case studies are excellent in presenting the participants' experiences in a natural context (Houghton et al., 2013). Voice-centred relational analysis (VCRA) was used to analyze the data. This method focused on the voices of the participants through various readings of the data, including readings on the self and identity. Presenting the case studies using a narrative method shared the experiences of the family in a meaningful and engaging way while also adding to the literature on roles, relationships, and identity through analysis. This study used a narrative approach to elicit stories about the life experiences of people living with dementia and their families. The significance of sharing participants' personal experiences with dementia can benefit the community by being transparent in sharing the experiences of people living with dementia. People living with dementia and their families should be able to voice their experiences without stigma, and this study narrated their experiences to share them with the world.

4.2 Study Population and Recruitment

Participants were recruited through connections with the community in Northwestern Ontario. A purposive sample of participants was recruited from an advocacy group for people living with dementia and their informal care partners, and a community program for families and people with dementia]. The advocacy group is supported by the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University, which runs a community program for families and people with dementia. The advocacy group has helped organize conferences about living well with dementia and is constantly engaged in advocacy within the community by raising awareness about the stigma associated with dementia. They have presented the “Through Our Eyes” presentation, a presentation about living with dementia, to community organizations and post-secondary classes to spread awareness about the experiences of people living with dementia. [A community program for families and people with dementia] is a social engagement program for people living with dementia and their families to gather and socialize with others, which is offered by CERAH, Lakehead University, in partnership with a community organization. It is held once a week at a community location, which houses a local coffee shop and is a place for people to meaningfully participate in social activities in a safe and inclusive environment. People living with dementia who live in the community and those who live in a long-term care home attend [a community program for families and people with dementia] with their families. Many individuals who are involved in the ADVOCACY GROUP are also participants of the community program for families and people with dementia.

I have connections with the advocacy group and the community program, which provides an insider effect. I am a student researcher at CERAH, and I am the Coordinator for the community program. I see these groups multiple times a month and have built relationships with these people. My goal was to conduct research with the group, and not on the group. Maintaining relationships and making sure participants’ voices were heard were important to me.

This study was not advertised to the general public. Participants of this study were recruited by myself and my committee. Potential participants were contacted at the community pgoram or the advocacy group meetings and asked to join this study with a brief outline of the study aims. The information sheet and consent form were offered at the time of recruitment. There was no incentive to participate.

The initial sample size recruitment goal was three cases. Each case represented one family. First, a person living with dementia and their informal care partner were recruited by myself and my committee. The person living with dementia and their informal care partner suggested 1-2 members of their family to recruit for participation in this study. As a result, each case had a maximum total of four people: a person living with dementia, an informal care partner, and 1-2 family members. After discussions among researchers during data collection, researchers decided to recruit four families. In the end, we had four families with 3-4 members each, including the person living with dementia. The study had a total of twelve participants (3 people living with dementia and 9 family members).

Table 1

Participant information

Family #	**Pseudonym (Gender)**	**Age**	**Relation to person living with dementia**
Family 1	Erika (Woman)	88	Person living with dementia
	Janet (Woman)	64	Eldest daughter
	Judith (Woman)	58	Youngest daughter
Family 2	Daryl (Man)	71	Person living with dementia
	Seija (Woman)	70	Wife
	Charlie (Man)	42	Youngest son
	Sophie (Woman)	11	Eldest granddaughter
Family 3	Caroline (Woman)	79	Person living with dementia
	Charles (Man)	80	Husband
	Aurora (Woman)	57	Eldest daughter

Family 4	Evelyn (Woman)*	81	Person living with dementia
	James (Man)	81	Husband
	Michelle (Woman)	55	Youngest daughter

Note. Table 1 includes information on participant pseudonyms, age, and their relation to the person living with dementia. *Evelyn did not participate in interviews or focus groups.

4.3 Inclusion and Exclusion Criteria

The inclusion criteria for participation for a person living with dementia included that the participant was a person living with a dementia diagnosis. Specification of the type of dementia did not need to be addressed in this study; however, a diagnosis of dementia was required to participate. The length of time since a dementia diagnosis or stage of dementia did not limit participants, as participants of any stage of dementia were invited to participate. The individual living with dementia had to live in a long-term care home for over 3 months to be included. This was because it was likely that after a period in a long-term care home, there may have been changes in the sensitizing concepts of interest (i.e. identity, roles, relationships, etc.) which added to the participants' stories. The people living with dementia included in this study had lived in a long-term care home for a range of 1-2 years at the time of data collection. The use of purposive sampling in combination with a long-term care home in the inclusion criteria was strategic to recruit multiple families for participation.

The inclusion criteria for the participation of members within each family were determined by the person living with dementia and their family members. It was not determined by researchers to include or exclude participants who had been selected by the person living with dementia. Although this was a broad inclusion criterion, it was important to this study because strict definitions of family in dementia research have produced uniform research in past studies.

The participants' self-determined definition of family added to the body of literature by producing unique and diverse representations of family relationships. All participants were fluent in English.

Exclusion criteria excluded people living with dementia living within the community because of the study's focus on long-term care homes. Furthermore, age was not in the exclusion criteria because participating family members can include participants of any age, including children or grandparents. The avoidance of an age restriction for participants was to highlight the importance of intergenerational relationships in families.

4.4 Data Collection

Data collection was conducted through one-on-one interviews and focus groups with participants, in addition to a short demographic survey. Demographic details such as age, length of marriage, and length of time in a long-term care home were addressed through a demographic form that was completed before interviews. One-on-one interviews with participants were important for sharing more nuanced and emotional personal experiences with the researcher. Interviews are often used as an exploratory method that focuses on the experiences of people, including their daily life, their culture and background, and individual experiences (Kelly, 2010). The use of interviews can be used to explore perceptions of the self and elicit stories from participants (Kelly, 2010). In this study, the use of interviews was a method to explore the roles, relationships, and identities of the participants.

The use of focus groups allowed family members to accompany one another and increased the potential for discussion when answering the questions. Focus groups emphasized the interactions between participants and were held with the person living with dementia and their family members. Focus groups allowed people to contribute to the conversation and add details to other people's experiences within the family while also providing data through group dynamics (Barbour, 2010). Oftentimes, participants of focus groups are able to understand and contextualize their experiences in focus groups (Barbour, 2010). In this study, family members had the opportunity to discuss what family meant to them in a group setting to facilitate discussions about their perspectives.

Interviews were chosen instead of fieldwork because they were a better fit to explore the topics of this study. Interviews can explore the unbounded social realities of individuals, in contrast to fieldwork, which is often bounded within the setting of the observations (Kleinman et al., 1994). Interviews provide information about people's identities, experiences, and self-reflections at a more in-depth level than fieldwork provides (Kleinman et al., 1994). Fieldwork does not often reveal the feelings, beliefs, and experiences of participants in the way that interviews do (Kleinman et al., 1994). Interviews are more personal and in-depth, which allows participants to be more vulnerable with researchers (Kleinman et al., 1994).

Interviews and focus groups followed a semi-structured interview guide of open-ended questions (see Appendix B). Additional probes followed some questions when participants did not understand the question, or the discussion strayed from the topic of interest. Examples included "Tell me more about [topic]" and "Could you explain this further?" This allowed individuals to add details to their answers and provided researchers with similar themes to follow. These data collection methods were chosen because of their ability to guide participants through the conversation without drawing out specific answers. Semi-structured interviews facilitated conversations full of empathy and rapport among participants and researchers (Smith & Osborn, 2004). Additionally, it produced rich data due to the flexibility of responses (Smith &

Osborn, 2004). The experiences and opinions of participants were expressed without significant participation by the researcher.

This study also had alternative interview guides that were shorter and easier to follow for interviews with people living with dementia and children. The use of alternative interview guides helped facilitate conversation by using short, clear questions and providing prompts when necessary. Furthermore, qualitative methods, such as reviewing pictures, were helpful in facilitating conversation. I asked families if they were willing to bring family pictures that they would like to view in the interview and use as a prompt. The person living with dementia and their family members looked through the family pictures and shared their family stories through the use of pictures. This provided an opportunity for them to share who they considered family by viewing the pictures together. Featuring visual prompts was an excellent tool for eliciting feelings, memories, and engaging with others (Leike et al., 2021). Riessman (2008) explained that visual prompts like pictures can restore feelings and "[transform] what was a private experience of the patient to being a shared comprehension of illness." Using pictures in focus groups encouraged collaboration and engagement among family members and allowed participants to express their beliefs, feelings, and opinions (Leike et al., 2021). Using family photographs elicited conversation about setting, events, and relationships with people in the pictures, which provided rich data for analysis. I think this was a helpful method to add to the experiences of people living with dementia and their families. This data collection method also allowed people living with dementia and young children to contribute easily without having to follow an interview guide. Pictures were not shared in the final paper to maintain the confidentiality of the participants and their families.

Some strategies used during interviews included using open ended questions, using visual prompts (i.e. pictures), and being flexible. Open-ended questions allowed participants to discuss what they thought was important in their answers. They were meant to guide participants, but not force specific answers from the participants. Open-ended questions were also helpful in interviews with people living with dementia because they allowed participants to share their experiences and allowed for flexibility in their answers (Conway et al., 2023). Visual prompts were used to elicit memory for people living with dementia which increased participation in interviews and drew out meaningful responses. Using personally relevant photos, like those of past or present family members, helped them express their experiences and feelings more than non-personal photos (Dalemans et al., 2008). The use of visual supports helped elicit in-depth responses to the interview questions because the visuals improved comprehension (Dalemans et al., 2008).

I wanted to make sure that participant voices were heard and that family members were not the only perspectives explored in the interviews. This was encouraged through patience with the people living with dementia and by making sure I directed questions to the people living with dementia to make sure they felt included, respected, and heard.

Interviews and focus groups were recorded with the consent of participants. Recordings were important to providing transcripts for analysis post-interview. They were necessary for the interpretation of the data as recordings highlight pauses, false starts, and laughter during the interview (Smith & Osborn, 2004). These seemingly small behaviours added to the data in meaningful ways and provided details that spoken words could not describe. Interviews were conducted where the participants felt most comfortable (i.e. at the community program in another room, at the participant’s house, at a long-term care home, at a coffee shop, etc.).

4.5 Data Analysis

Data analysis was conducted using a voice-centred relational approach (VCRA). VCRA is a method of analysis that is highly applicable to qualitative studies focusing on the self and identity, as these concepts are embedded in the analysis strategies. Each case was presented using a narrative approach to narrate the stories and experiences of people living with dementia and their families. Each family was presented as a case, as discussed previously.

The method of analysis used was a qualitative method called voice-centered relational approach (VCRA). It is commonly used in narrative research because VCRA focuses on the narratives of the participants, including stories, perspectives, and values (Bright, 2016; Gilligan et al., 2003). A Listening Guide was used as an analytic tool and consisted of four readings in data analysis (Bright, 2016; Gilligan et al., 2003). The Listening Guide helped listen to the voices within the narrative, understand how, when, and why these voices are used, and explore the relationships between voices and within different contexts (Bright, 2016; Gilligan et al., 2003). It requires four readings of the data collected:

Reading 1: The story and response) The first reading examines events, characters, and recurrent phrases, and the researcher's emotional and intellectual responses to the participant's interview (Bright, 2016; Gilligan et al., 2003; Mauthner & Doucet, 2003). It allows the researcher to place themselves, their background, and their history in relation to the participant's story (Gilligan et al., 2003; Mauthner & Doucet, 2003). It acknowledges that assumptions and previous perspectives may impact the interpretation of the data (Mauthner & Doucet, 2003). This provides a rough idea of the story to be built from in the following readings (Bright, 2016). Some questions to ask as a researcher could include "what is going on here?" and "what is my reaction to this story?" (Bright, 2022). In my analysis, I wrote notes on the family's story, including making a rough timeline of events, and noted my emotional responses to reading the transcripts. Writing about my emotional responses to the initial readings provided insight into previous assumptions I may have had or my beliefs about what family is.

Reading 2: Participant voices) Next, the second reading looks at the participants' experiences, feelings, and way of speaking about themselves by analyzing the voices in the narrative (Bright, 2016; Gilligan et al., 2003; Mauthner & Doucet, 2003). This reading is where researchers begin interpreting the participant's perceptions of the self by looking for the presence of pronouns (i.e. I, we, you, etc.) (Bright, 2016). The second reading can help to identify the different voices a participant speaks with and in which context they are using these voices in (Bright, 2016; Gilligan et al., 2003). During the second reading, I went through the transcripts in NVivo and highlighted when and how participants spoke about themselves, including pronouns, descriptors, and roles that they attributed to themselves.

Reading 3: Others and relationships) The third reading explores relationships between people and the participant, as well as the participant's engagement with the others in their environment (Bright, 2016; Gilligan et al., 2003). This reading begins the interpretation of the participant's identity through the analysis of how they speak of other people in their stories (Bright, 2016; Bright, 2022; Gilligan et al., 2003). Specific words to look for may include 'they' or 'we' (Bright, 2016; Gilligan et al., 2003). During the third reading, I went through the transcripts in NVivo and highlighted when and how participants spoke about others, including descriptors or roles that they attributed to family, friends, or others in their lives.

Reading 4: Context) The fourth reading analyzes the relationships between the participant's story and broader social contexts, including socio-cultural contexts and the physical environment (Bright, 2016). The context that researchers are looking for can be visible (i.e.

setting, housing situation, etc.) or invisible (cultural values, etc.) (Bright, 2016; Gilligan et al., 2003). The last reading is important for providing context and background to the participant's narratives (Bright, 2016). Additionally, the fourth reading may be specific to the researcher's topic of interest, like "justice" or "resilience" (Bright, 2022; Gilligan et al., 2003). For example, in this study, the fourth reading explored the concept of family and its meaning to individuals and groups. In my analysis, I coded values, settings, and family circumstances in NVivo and added to the family stories about the family's situation.

Voice-centred relational method was beneficial in this study because of its rigorous methods of analysis and its consideration of different perspectives in the narrative. Due to the embedded analysis of participants' voices, the self, relationships with others, and participants' identity, VCRA was beneficial in this study in answering the research questions about relationships and identities. It was a rigorous method that provided very meaningful results. This method excelled in amplifying voices and sharing the context in which the stories occurred and enabled the exploration of people's dementia journeys and the impact dementia had on the family unit.

Some suggestions and strategies for conducting VCRA included building a narrative, minimizing participant numbers, and purposefully selecting data. Bright (2022) suggested building a narrative at the first listening and continuing to add to the narrative until the last listening. I began to build the family narrative after the first listening of each interview within a family. A small sample of participants is most effective for conducting this type of qualitative study as it requires many readings and steps to analysis (Bright, 2022; Gilligan et al., 2003). Due to the number of readings and steps, I had a small sample of 12 participants in total. Purposefully selecting data to share in the final paper is necessary because sharing all of the participants' stories to an adequate depth is impossible (Bright, 2022; Gilligan et al., 2003). There is no correct way to present data in VCRA, but the main priority was to share voices and examine relationships (Bright, 2022; Gilligan et al., 2003).

Narrative case study approach includes developing an in-depth case description (Creswell, 2014; Yin, 2003). Case studies are bounded by time, setting, and context; therefore, it is important to include as much information about the case for the readers (Creswell, 2014). In this study, cases were bound by the stage of the dementia journey that the family was experiencing, the family dynamics, and other factors that were unique to the family's experience. The description of each case was important for readers to understand how researchers came to their final conclusions about the case and draw their own conclusions (Creswell, 2014). Saldana (2013) suggested that narrative approach was suitable for studies about the development of identity, social meanings and values, and narrating life course. The exploration of the self and identity was incorporated in this study by using VCRA for data analysis.

When using narrative case study approach, the method of telling a story was important. The story was based on the participants' life experiences, so truthfully telling the story was a primary goal in data analysis and presentation. A component suggested by Riessman (2008) of presenting a narrative case study included the visual analysis and interpretation of images by participants and the stories told about the image. Special attention to the interactions around the pictures that participants brought to the focus group were made. How people discussed their family members, who they deemed to be family, and the stories they told were analyzed.

The interpretation of narratives has been briefly explored in past research with people living with dementia (Crisp, 1995; Crisp, 1999). Previous researchers have said that people living with dementia often mix up stories and facts; however, oftentimes they are not sharing false information or lying on purpose (Crisp, 1995). Although some of the specific details about the stories people living with dementia are telling may be false, they are still recognizable narratives in structure (i.e. characters, setting, beginning-middle-end of the story, etc.) (Crisp, 1995). The difficulties researchers face in their interpretation of the narrative may be due to a lack of sense-making strategies on the part of the researcher, rather than the absence of sense in the story told by the person living with dementia (Crisp, 1999). Crisp suggested that the act of story telling and what it means to tell a story are what researchers need to focus on, instead of the truth and reality behind the narratives (Crisp, 1995). This is an important consideration in research with people living with dementia because their stories provide researchers with insight into their reality and experiences. Additionally, it was discussed by Crisp (1995) that reminiscing and story telling were ways for people living with dementia to affirm their identity. Being listened to as they told stories helped individuals maintain their self-esteem, self-identity, and worth, whether the stories were true or false (Crisp, 1995). Regardless of whether the stories of the past were true, people living with dementia were capable of the emotional, social, and imaginative aspects of story telling (Crisp, 1999).

4.6 Data Management

In qualitative research with vulnerable people, such as people living with dementia, data management is important. Data was stored in two locations: a password-protected Google Drive folder and a password-protected personal computer. Emails with data were sent to approved contacts (i.e. participant or committee member email addresses). Raw, unedited data (i.e. audio files) were stored in a separate location within the Google Drive from the anonymized data (i.e. transcripts, data analysis, etc.). Contact information for the participants was stored in a separate location from the data. Separating these forms of data was important in maintaining the confidentiality of the participants.

4.7 Research Rigour

Maintaining rigour in qualitative research is important to ensure the credibility, dependability, confirmability, and transferability of the study. Strategies such as prolonged engagement, peer debriefing, and member checking were some of the strategies that were utilized in this study to ensure credibility. Prolonged engagement with the data typically involves spending time in the field in order to engage with and understand the experiences of participants (Houghton et al., 2013). I have been, and continue to be, engaged with people living with dementia and their families every week at the community program and the advocacy group. Member checking with participants after transcription and peer debriefing with committee members during data analysis was important to maintaining consistency, confirming data, discussing themes, and ensuring credibility (Houghton et al., 2013). After transcribing and anonymizing the interview audio recordings, I sent transcripts to the participants for them to review. I reminded participants that the study would be published for public access. I ensured that participants were aware that they could redact anything from the transcript before my data analysis, and they were able to make any changes up until the presentation and publication of the final thesis.

Dependability and confirmability within a study involve an audit trail that was saved on NVivo software, Google Drive, and my personal computer. Data will be stored at CERAH after the final thesis has been completed. I wrote in a reflective journal throughout my thesis that included the different stages of research decision-making through the thesis development process. The journal entries highlight important decisions in the research process, including discussions with committee members, rationale for choosing research methods, and the interpretations from the data. Additionally, the journal included reflections from my perspectives of family, including my roles, relationships, and identities I had with my family, and my assumptions and personal definitions of what family meant to me. I was considerate in my perspectives on family in every stage of developing and conducting this study. My committee and I ensured that the findings of this study reflect the data, not the opinions or perspectives of the researchers. The reflective journal was a combination of paper and electronic documents stored in a safe location. The reflective journal will be stored with paper research documents at CERAH.

4.8 Ethical Considerations

There were many ethical considerations regarding working with people living with dementia and family members. Prior to data collection, approval from the Lakehead University Research Ethics Board was acquired. The TCPS2 certificate for ethical conduct in human research was completed by all members of the committee.

Vulnerable groups such as people living with dementia and children participated in this research. It is important to continue to research the experiences of people living with dementia. Although they may not be able to participate in the same capacity as other participants, their opinions and experiences are still valid and contribute a wealth of knowledge to the research. The continued fear and avoidance of including people living with dementia in research only perpetuates the harmful stigmas against people living with dementia. Participants were carefully informed of the nature of the research, the consequences of participation, and given alternative options (i.e. option to opt out of the study). Informed consent was brought to the participants' attention numerous times in the interview process. For those who were unable to give informed consent, including people living with dementia and children under 18 years of age, the power of attorney or legal guardian was contacted to obtain consent. Assent of people living with dementia and children was required to participate. Assent is an agreement obtained from participants that they are willing to participate. It requires a basic understanding of what is being asked for participation. People living with dementia and children were able to give assent and expressed that they were willing to participate in the study. For interviews with people living with dementia and children under the age of 18, it was required that the power of attorney or legal guardian remained in the room during the interview. This was to ensure that people living with dementia and children were comfortable during the interview with the researcher. The power of attorney and legal guardians were also helpful in facilitating story telling and clarify details which was helpful in data analysis.

All personal identifiers were removed from the participants' transcripts, including the removal of participant identifiers like names, locations, and other specific identifiers to protect the identities of participants on transcripts. This was an important and significant consideration because Thunder Bay is a tight-knit community, and many people know each other well. Individuals within the community program and advocacy group are very close to one another and can likely recognize stories and situations that their peers have experienced. This was a difficult issue that was addressed early in the interview process. Participants were informed about the risk of participating in the study when individuals within the group, community, and world would be able to access the information shared in the interview and in the final research paper. This risk was mitigated through the use of alternative names for participants. Each participant selected or was given a unique pseudonym at the interview stage. This pseudonym was maintained through data collection, analysis, and the findings of the study. The assignment of a name instead of a numeric identifier was to give a personal lens to the data and the narrative of the person. Numeric identifiers can inadvertently promote division between the data and the story, whereas a name fosters engagement with the very personal stories being shared.

I also considered the potential for harm to the participants through interviews, analysis, and interpretation of the data. Although it was not the aim of the interviews to elicit feelings of sadness, stress, or guilt and topics of struggle or conflict, I acknowledged that these topics were likely to be discussed at the interview stage. Whether directly asked about challenges the participants have faced with relationships and a dementia diagnosis, or if the topics were discussed through the participants' stories, there was the possibility that the interviews could elicit those feelings. Mental health resources for coping with stress and services available within the community were provided to participants before and after the interviews. Participants were reminded that they did not have to share information they were unwilling to discuss throughout the interview process. My contact information was available for all participants if they needed assistance.

The interpretation of data had the potential to cause harm to participants and those involved in the participants' narratives. This was why member checking with participants throughout the interview process and data analysis was important. After interviewing participants and transcribing the interviews verbatim, I sent the interview transcripts to the corresponding participants. Participants were asked if they would like to remove statements from their transcript that may cause harm to themselves or other family members if shared with their family or the public. Additionally, after analysis, the participants were contacted again to confirm interpretations of their narratives. This was important for ensuring that participants' voices were heard and properly interpreted in a manner that was respectful and considerate of their stories while also preventing potential harm to other family members. I did not want participants to feel as if I took their stories and wrote my interpretations of them without considering the harm that could be done to their families. With my thesis committee and participants, I discussed difficult details from participant stories. We discussed whether to include these details in the final thesis or omit them entirely. Gaining permission to share sensitive details was important to my committee because we wanted to ensure that the person living with dementia and the family were portrayed in a way that was respectful. I aimed to present a sensitive portrayal of their family stories that was truthful and respectful, with as much participation and engagement from participants in the member checking process as possible. In cases where I was unsure about the potential for harm, those quotes and information were redacted from my findings.

Another important ethical consideration to reflect on when using a narrative approach is re-storying narratives. As a researcher interpreting and retelling the narratives of people living with dementia and their families, I asked myself, “Whose story is it that I am telling?” and “Whose story is it to tell?” I think that the owners of the stories are the people living with dementia and their family members. Although I am conducting research on these individuals and rewriting and reconstructing their stories, it was their voices that I was presenting. Stories need to be respected, so I was member checking the data with participants at multiple points of data collection, transcription, and analysis. I wanted to ensure their voices were heard, represented well, and respected throughout this study. I ensured that they were aware that their stories were their own and that the sole ownership of their shared narratives belongs to them. I think the stories' authors were the participants because their stories belong to them. Although I was presenting their stories in the form of this study, the true authors of the story were the people living with dementia and their family members. Acknowledging and respecting that their stories were theirs to share and giving them full ownership of their stories demonstrated the respect and consideration I continue to have for my participants. Lastly, the findings were presented to some participants and a small group of the public attending my thesis defence. Participants who attended were asked how they felt after the presentation, and they said that they were comfortable with how their family was portrayed. Although they said they were comfortable with what was shared about their families, I decided, upon recommendation of my committee, to redact some personal parts of their stories to protect participants' confidentiality.

Writing and documenting people's lives through research can create challenges and ethical concerns as well. There is a permanence to writing and print that is different from sharing the spoken word (Josselson, 1996). A reflection Josselson (1996) had was how do people feel about the experience of being written down and analyzed? This highlights the importance of member checking throughout the research process because participants should have the opportunity to advocate for themselves in how they will be presented in the final thesis and potentially published to the world. The intimate, personal stories of family experiences are shared in the final thesis, which can be intimidating and, at times, uncomfortable to think about; however, strong relationships, constant communication, and member checking among researchers and participants helped comfort participants about their stories being shared. Ensuring that participants felt like I accurately and respectfully interpreted and retold their stories was important to me.

Before the final submission of the thesis for the public to view, I decided to redact more details from family stories and findings upon recommendation from my committee members. This was, in part, due to the permanence of the written document and ensuring that details were removed that may inadvertently harm participants. Where information was critical to the findings of the research, I attempted to summarize participants' experiences, rather than presenting specific quotes or examples. This was not necessarily an oversight, but a decision we made as researchers to carefully consider the impact our research has on people near to us.

The impact that this research can have on the participants of this study and people around the world was another important ethical issue considered. I considered how research has the power to influence people's perception of dementia and combat the stigma around dementia. To address this, I carefully considered the language used in the paper by using person-centred language.

It should be acknowledged that I had well-established relationships with many of the members of the advocacy group and community program during this study. The relationship between the researcher and participants was recognized prior to conducting research on this group of individuals. This was important to highlight because it built rapport among researchers and participants and facilitated a more in-depth and honest discussion in the interview process. Using the interviews as a research process, instead of a research instrument, helped generate trust and understanding at a more personal level. Members of my committee also had close relationships with members of the advocacy group and the community program. We reflected on our positions as volunteers, advocates, and friends of people living with dementia, and we concluded that there were no conflicts of interest in this study.

4.9 Methodological Limitations

There were many limitations to consider regarding the methodology and the study design itself. The study was specific to this group of participants' experiences and bound by time and context. Case studies are meant to share cases that can be recontextualized to similar situations and provide insights into the case at hand (Hellstrom et al., 2005). Instead, the power of this study and this approach to analysis was that it highlighted the impact of a dementia diagnosis on relationships within a family.

The open nature of semi-structured interviews can benefit researchers by highlighting novel ideas and experiences from the participants, but can also limit the control a researcher has over the situation (Smith & Osborn, 2004). This can include challenges like control over the location, control over the direction the interview takes, and other challenges related to the topics of the interview (Smith & Osborn, 2004). The lack of control can be overwhelming for researchers. It can lead to interviews that do not produce data related to the topic of interest (Smith & Osborn, 2004). To combat this limitation, I implemented redirection techniques to kindly guide participants back to the questions asked during the interviews and focus groups.

There was a commitment to the in-depth analysis of each case, which limited the number of participants who were involved in the study. Although this was named as a limitation, it also acted as a strength. I was able to explore the data and produce profound, in-depth analyses because I had fewer interviews to analyze.

Some limitations to consider about the narrative method of analysis and in presenting the research findings included the subjectivity and validity of the interpretations, the lack of standardization, and the potential for confirmation bias. It was important to recognize that the subjectivity and validity of the study were determined through the interpretation of the data and results. There can be multiple interpretations of the data because qualitative data is subjective.

There was no standardized method of collecting, interpreting, or presenting data in narrative analysis. Due to the lack of standardized methods, people often overlook qualitative research because it “lacks rigour” or “does not follow detailed procedures.” Narrative research should not be overlooked because of a lack of standardization but should be appreciated for its unique and focused approach to sharing participants' experiences.

Including individual and group level data added interesting data and highlighted relationship dynamics among family members. Although individual and group levels of data and analysis added unique perspectives, they also posed analytical challenges. Different accounts or interpretations of events from participants within a family made it difficult to combine. Multiple perspectives from family members were shared, and prioritizing and representing perspectives fairly could be a limitation. There were challenges in sharing the data in a clear and consistent way that readers were able to follow when sharing data from individual and group levels. These limitations in methodology were considered while writing and addressed with the committee.

The potential for confirmation bias with the use of any research approach is a topic of concern. Researchers' background knowledge, opinions, beliefs, and experiences shape their research in profound ways. Reflexivity by the researcher in the proposal, data collection, and data analysis phases of the study was required to confront these beliefs and how they shaped the research. Collaboration with peers at each stage of the study was important to avoid reliance on one researcher's interpretations. Continued reflective journaling through personal reflections on family meaning, definitions of family, and other related topics was described in my journal. I made sure to carefully consider my opinions of family in my analysis of the data through reflecting and journaling. I was very conscious of my assumptions and ensured that my definition did not interfere with the definitions families developed and shared with me. Although there were no strict hypotheses in this study, there were some topics that were looked at more carefully, such as the roles, relationships, and identities of people living with dementia and their family members. Nevertheless, illustrating the complexities of relationships by presenting both the positive experiences and the challenges showed the truth of people’s experiences with dementia.

4.10 Summary

In summary, this study used a narrative case study approach to explore the stories of four families and their dementia journeys. Data was analyzed using voice-centred relational approach (VCRA) in order to explore the sensitizing concepts of roles, relationships, and identities. Participants were recruited from a local advocacy group and a local community program for families and people living with dementia. Researchers considered many ethical and rigorous considerations in conducting this research with vulnerable populations, such as people living with dementia, older adults, and children. As mentioned previously, although the stories in this study have been written down by the researchers, they belong to the participants. I am fortunate to have been able to share these stories with the world and am grateful to the participants for sharing their stories.

Chapter 5: Family Narratives

5.1 Introduction

The following section features four family stories in their own words. The purpose of sharing the family story is to provide a backdrop with details and context about their family history and dementia journey and illustrate relationships through stories. Presenting the data in this way is helpful in presenting voice-centered relational approach because it presents the first reading (the story) to the readers before diving into further analysis in the findings section. In its own unique way, Chapter 5: Family Narratives is a chapter of findings. I decided to present the narratives in Chapter 5 and the findings in Chapter 6 because they use different methods of analysis. Chapter 5 uses storytelling to analyze the data and provide context. Chapter 6 uses thematic analysis and the three remaining readings of VCRA to analyze the data and explore themes.

Each family story features a cast of characters, including participants and other important members, to illustrate who is involved in the story. Each story is also told chronologically so that readers are able to follow the family storyline. Analysis of the families will be featured in the findings section of this paper. Excerpts from transcripts are used to describe the family narrative and provide context about the family. Using quotations from the transcripts brings authenticity to the stories and shares the raw, unfiltered perspectives of the families. Each story features the context or background information about the family, the person living with dementia's early life, and their dementia journey. The four stories are:

1) "Love without any expectations:" Erika's family story in their words
2) The family team: Daryl's family story in their words

3) Making up for lost time: Caroline’s family story in their words
4) “My mom is an angel:” Evelyn’s family story in their words

It is important to acknowledge that these stories belong to the families. Although I wrote the stories as part of my thesis dissertation, these stories are the real-life experiences of real people. These people were gracious enough to share their life stories to feature in my thesis dissertation, for which I am incredibly grateful. The ownership of these stories is entirely with the participants and their families.

5.2 “Love without any expectations:” Erika’s family story in their words[1]

5.2.1 Context

Erika was 88 years old and living with dementia. She immigrated to Canada at 17 years old from Eastern Europe. Erika was the mother of two adult daughters, Janet and Judith. Janet was 64 years old, and Judith was 58 years old. She had four grandchildren and two grand-dogs. Erika loved fashion and was often dressed fashionably. From her time in Europe to the present, Erika loved to accessorise and wore nice clothing. Erika enjoyed going to her daughter’s camp and spending time lounging in the chairs outside during the summer.

Family #	Pseudonym (Gender)	Age	Relation to person living with dementia
Family 1	Erika (Woman)	88	Person living with dementia
	Janet (Woman)	64	Eldest daughter
	Judith (Woman)	58	Youngest daughter

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[1] Some details of Erika’s story are redacted to protect participants’ privacy and confidentiality.

5.2.2 Early life

Erika was born in Eastern Europe in 1936. She was a child during World War II, while Eastern Europe fought in the war. After World War II, the communist government of Russia (the USSR at the time) occupied much of Eastern Europe. Even during the occupation, people still found ways to enjoy life. At the age of 16, Erika and her best friend rented a room together in a large city in Eastern Europe and worked at a linen factory. Although they had been friends for a while, this period of time was "the peak of their friendship." Erika spoke to Janet about her friendships in Europe. Janet described Erika's friendships by saying, "Yeah, she says, 'honey, like I would have- we would get paid and the first thing we would do is buy a dress and shoes. And we might have enough for one loaf of bread.' I'm like, what? When we were in [her country] with her, she brought us to [square] where she danced every Saturday night. It was just amazing."

However, Erika soon realized that she did not want to live in a communist country. During the revolution, Erika fled Eastern Europe with her two friends at the age of 17. Janet painted a picture of Erika's experience by saying, "Mom and her two friends managed to escape [country] with the Russian forces on their heels to [neighbouring country], being shot at as she then crawled through the field to get to the [neighbouring country's] border. Mom was provided transport, then she went to [city], England and stayed there for six months." From England, Erika travelled to Canada by boat and train to Manitoba and finally settled in Ontario.

5.2.3 Life in Canada

In Ontario, Erika met her first husband. They had two daughters, Janet and Judith. Having immigrated to Canada with only her younger brother, most of her family was back in

Europe. Regardless, Erika built a life for herself in Canada. She focused on her family and provided everything she could for them.

Erika's daughters described Erika as a very loving individual. Her daughters said she always showed love and care to her daughters and grandchildren, whom she adored. Janet said that Erika never had any expectations when she showed love for someone; it was unconditional love that Erika had for her family. Janet said, "So yeah, she was, and she's always, *always* given us love without any expectations. She's just a very loving individual, and she's always wanted her family around her, providing for them in any way she could." When Erika visited Janet's house and saw Janet's husband, she often said to him, "I love you. It's so nice to see you." Her daughters expressed how they have always felt their mother's love through every stage of life.

Erika was not only a mother to her two daughters, but she was also a protector. "She was everything to us," said Janet. Erika gave her daughters the best life that she could, and Janet and Judith admired their mother for her strength. "She was the supplier of things," Janet said, "She would clean houses so that we could have presents under the tree." Erika's love for her family was evident in the care she offered to those close to her. Despite experiencing challenges during the war in her youth, Erika did not tell her daughters to be grateful for the life she had given them. "She never reprimanded us in saying, you know you should be grateful that you have such good life," Janet said, "It was always with kindness." Although Erika went through difficult times in Europe, she did not let those experiences influence how she raised her daughters: with love and kindness.

Erika loved fashion. The stories told by Janet and Judith about Erika as a teenage girl in Europe looking for pretty dresses to wear to dances spoke to her eye for fashion. Erika wore very nice outfits and accessories when she dressed herself. She dressed her daughters well when they were children. Her daughters continued to go to her for advice on what to wear even after Erika's diagnosis of dementia. Janet said she brought a new clothing item to show her mom in the long-term care home and Erika touched the material and said, "love it." Even at the community program, she complimented the volunteers by saying "very pretty" or "cute" while gently touching the outfit's material.

Janet and Judith told much of the family story in Erika's family. Between her life in Canada and her dementia journey, Janet and Judith did not share many details of Erika's life during this time period. As a result, there was a gap in the family narrative where the daughters shared their childhood memories of their mother and then discussed the beginning of Erika's dementia journey. Although this did not provide the full picture of the family narrative, it illustrated how participants told stories and shared what they thought was important.

5.2.4 The dementia journey

Erika's dementia journey started in 2018. Symptoms started occurring after her second husband, Danny, was diagnosed with a neuromuscular condition. In 2018, when Danny's condition required him to be in a wheelchair, Erika and Danny moved into a wheelchair accessible condominium and sold the home that they loved. Seven weeks after moving into the condominium, Danny's condition progressed to the point where she had to move into a long-term care home.

While Danny was in a long-term care home, Erika started displaying different emotional responses. Her friends started noticing issues with memory and forgetfulness, agitation, and erratic driving. Judith said that she started to see some changes in Erika, "[…] I can remember those times when like she – there was a lot of agitation, and think it was because she was confused. She didn't know what was going on and she was getting - she got really angry if she couldn't remember something or, you know, did something that she normally wouldn't do. And yeah, there was a lot of aggression at the beginning.” Janet said that since she was caring for Danny in palliative care, she did not realize the changes in her mother’s actions until later. “When your parent is dying and you know it's inevitable and it's getting worse by the day, you spend less and less focus on anybody but that person,” Janet said, while explaining why she did not notice signs in her mother sooner. In 2021, Danny passed away in a long-term care home. One month after Danny’s passing, Erika was diagnosed with dementia.

At the first appointment with the geriatrician, the specialist told Erika that they were taking away her driver’s license because of the signs that Janet and Judith discussed. This made Erika upset, and she tried to leave the appointment. Later, she refused to go back to the geriatrician for any follow-up appointments. Janet had to pretend they were going to visit someone at the hospital and, when they arrived, convince her to go into the geriatrician’s office. But she was not just angry at the doctor; she was angry at her daughters. Meanwhile, Janet and Judith were trying their best to deal with their mother, who was, as the daughters described it, resisting care.

With Erika no longer permitted to drive, Janet and Judith had to make the difficult decision to remove Erika’s car from her possession. “We had to sneak in the garage at the condo and take her car out and said that it needed repairs and that we just had to bring it to the garage,” Judith said, “And then she never got it back.” Erika started asking, “Where’s my car?” and her daughters would tell her that it was still in the garage. When Erika figured out that her car was not coming back, she was very angry at her daughters. “But it was all in her best interest…” Judith said.

More signs arose after Erika’s diagnosis. There were smaller things like forgetting how to use the television remote after being instructed numerous times by her daughters, and bigger incidents as well, like microwaving tinfoil-covered items and nearly causing a fire. Janet and Judith had to remove the microwave from Erika’s condominium entirely after Erika ruined two microwaves. There were incidents with flooding in the condominium because Erika forgot to turn off the tap. There were incidents where she would put something on the stove and leave it on while the pots melted. To prevent further damage, her daughters started removing additional items, like small appliances, from the condominium. Erika complained to her friends that her daughters were taking things away from her condominium. In turn, her friends called Janet and Judith and told them the horrible things their mother said. Although it was tough to make those decisions, Janet and Judith knew that it had become too dangerous for Erika to live alone.

In 2021, Erika moved into an assisted living home. Erika did not want to be there and wanted to leave. She often left the home at all hours of the day. The staff did not stop her because at an assisted living home, residents can come and go as they please. There was a situation where Erika left at 8:00 PM and did not return. It was at 12:00 AM that the staff called Janet and Judith and told them that their mother had left and had not returned for four hours. In a panic, Janet and Judith drove up and down the streets looking for their mother in the middle of the night.

In the six months that she lived in an assisted living home, Erika was found at her old condominium, at a stranger’s house, and at the beer store. The first time, Erika had made her way back to her old condominium. Judith said, “So she would go out wandering the streets and then we'd have to go look for her. And there was one time I went to her old condo building, and there she was in there. And they all knew her at the door. So they said, oh, we let her in. And, you know, because we figured you would find her here eventually. So I don't know how she made it from there to there." Another time, Erika had been knocking on doors and a kind couple let her in. They searched through her purse, found her identification, and found a phone number for Judith's mother-in-law. After a few calls, Janet was able to pick up Erika from the couple's house. Another time, Erika walked in only her housecoat to the beer store, and the beer store employees were quite concerned. They sat her down with paper and pen to keep her busy while they called the police, who arrived and escorted Erika back to her assisted living home. When asked about the encounter by her daughters, Erika simply gushed about how handsome and good-looking the policemen were. It was after this incident that Erika's daughters realized that Erika needed to have 24-hour care.

After the situation at the beer store, Janet and Judith had Erika added to the long-term care home waitlist. After two days, a bed in a long-term care home was available and Erika moved. She moved into a locked unit, which is a floor where residents are unable to leave due to the locked doors. She did not enjoy it there either. Judith said, "She kept wanting to leave and she couldn't understand why she couldn't leave. […] She would not take her coat off. […] It took like, months before I think she finally didn't wear her coat constantly and grab all her stuff to try to leave." During this time, Erika was very angry with her daughters. Sometimes they took her out of the long-term care home for dinner. After dinner, they drove her back to the long-term care home and she said, "No, no, I don't want to go back." She fought her daughters getting out of the car, into the building, and off the elevator. "She would actually be punching and hitting me," Judith said, "… it was hurtful. You know, picture your mom punching and hitting you and swearing at you, and when you're just trying to do the best thing for her. Like, you can't just ignore that and, you know, pretend like it doesn't bother you because it does."

It took some time for Erika to settle into the long-term care home. Janet and Judith said that after a while of adjusting her medications, the doctors finally found a dosage that had her in a calming state. Some of the emotional responses, like anger, wore off. Her daughters said Erika has accepted that she lives in the long-term care home. Today, Erika still lives in the long-term care home. She is calm, sweet, and gentle with everyone around her. She engages with her fellow residents and is often found helping the nurses with their rounds. She compliments people at the long-term care home and the community program. She kisses the cheeks of the community program volunteers and greets everyone with a smile.

“We know what road lies ahead, it’s inevitable what happens with dementia,” Janet explained when discussing the next part of the dementia journey. “We've started mourning my mom's death from the time of diagnosis. And that's a long mourning period.” The grief and loss that Janet has felt for a long time about the journey has been “emotionally draining.” Erika’s dementia progression led Janet and Judith to face the inevitable: death. When Janet spoke about talking to others about the dementia journey, she said, “So you can talk to someone about your journey, but it may never be their journey. The only thing is it's inevitable what the end will be, and so, embrace every moment you have left, dance, love, just be with them.”

5.3 The family team: Daryl’s family story in their words

5.3.1 Context

Daryl was 71 years old and living with dementia. He was married to Seija (70 years old) and they had two adult sons, Stephen and Charlie. Stephen was 47 years old, and Charlie was 42 years old. Stephen lived in a different province with his wife Jessica and two sons, Mason and Dex. Charlie lived in the same city as Daryl and Seija with his wife Rose and his two daughters, Sophie and Abigail. Daryl was a big Toronto Maple Leafs fan. He wore a baseball cap or a toque with the Leafs emblem on it almost every time he went out. He collected hockey cards for years and had a framed collection of signed cards from the players of the Leafs when they last won the Stanley Cup in 1967.

Family #	**Pseudonym (Gender)**	**Age**	**Relation to person living with dementia**
Family 2	Daryl (Man)	71	Person living with dementia
	Seija (Woman)	70	Wife
	*Stephen (Man)	47	Eldest son
	Charlie (Man)	42	Youngest son
	Sophie (Woman)	11	Eldest granddaughter
	*Abigail (Woman)	9	Youngest granddaughter

**Did not participate in interviews or focus groups.*

5.3.2 Early life

Daryl was an admired member of the community. He was an elementary school teacher for many years before his retirement in 2012. His contributions to the community were still apparent, with initiatives that he started many years ago continuing to thrive in recent years. The Christmas drive that Daryl started, which gives to families in need, continued at the school where he taught for most of his teaching career. The admiration for Daryl by his students and their families was evident in the thoughtful gifts given to him over the years. One year, Daryl received a particularly special gift. Signed hockey cards from members of the Toronto Maple Leafs 1967 Stanley Cup winning team were framed and gifted to Daryl with a letter as a thank you. “Well, then I found a letter that went with that [….] If you read this, you would cry,” Seija said, “And it's just amazing.” Seija’s pride for Daryl showed in her descriptions of his achievements as a teacher and his impact on the community.

Daryl loved the Toronto Maple Leafs hockey team. His love for the Leafs showed in his choice of vehicle colour (Leafs blue), his outfit choices (Leafs merchandise), and his passion for watching a Leafs game. Many of the photos that his family kept showcased Daryl in a Leafs jersey, baseball hat, toque, or other Leafs-themed clothing. His family showed photos of Daryl on the ice at the Scotiabank Arena in Toronto when he got to meet some of the Leafs players. Daryl stood next to a Stanley Cup fire pit at a friend’s camp one summer, and someone took a photo of him smiling next to it. His passion for the Leafs did not fade with dementia. He smiled every time the Leafs were mentioned and nodded in agreement that “this is their year!”

Daryl was a very friendly person. “You know, my father from a very early age always told my brother and I to… to try to be friends with everybody,” Charlie said, “And I think we sort of have always taken that to heart you know…” The impact of Daryl’s advice stuck with Charlie and Stephen. When describing his dad, Charlie said, “He wasn't loud, but he was always talking to somebody. Like if there is a person that… he didn't know in a situation, he was going to know them within like 10 minutes, whether they wanted to or not. And my mom is the exact same way. But she's just a lot… She's a lot louder than he is.” Daryl and Seija often met new people, just at different volumes.

Daryl had a sense of humour. At the long-term care home, Daryl had to take the elevator, so Seija distracted Daryl by dancing and singing. One day, Seija talked to the long-term care staff and said to Daryl, “Tell the ladies what we do in the elevator.” Daryl looked at the ladies and winked. Seija said, “No! No, we dance!” But Daryl knew what he said, and he was smirking the entire time.

5.3.3 The dementia journey

Daryl was diagnosed with dementia in 2020. Unfortunately, Daryl’s family members were not strangers to dementia. Many of Daryl’s family members had dementia. Seija explained, “Four had [dementia]. Two have passed already. One was 65 when he passed. His sister was, I think, 72. And she passed, it's going to be two years in November. [Daryl] has it now and then another older brother. And they lost their dad at 72 from dementia.” Seija cares for numerous people in the long-term care home, including Daryl, her mother with dementia, and her father as an older adult.

There were some early signs of dementia that Daryl’s family noticed prior to Daryl’s diagnosis in 2020. Seija noticed that Daryl started to decline invitations to a poker group that he had loved. She said, “Yeah, I think signs were showing quite a while before that because I would notice he was part of a poker group. There's a bunch of teachers in that group… But there's one of the guys had a little poker group. And he stopped going and he loved it.” Although Daryl was a math teacher, he started to struggle with numbers. “He was a math teacher and then he would say things like, ‘I can't believe that house is on the market for $300.’ But it was $300,000. So he was starting to struggle with math and of course he was trying to mask things for himself for a long time,” Seija said. She said that there had been signs for about 10 years before his official diagnosis.

The most striking thing that Seija noticed was in 2012 when Daryl spontaneously announced his retirement. “And another thing back in 2012, he came home from work. It was May. And he said, ‘I'm retiring this year’ which is really odd,” Seija said, “First of all, he loved teaching, and he had never even talked about retiring, even though he was going to make the early factor. […] And I thought that was odd. And he hadn't even sat down and said, ‘hey, [Seija], what do you think?' I'm really thinking about like we talked about everything. He didn't. He was just retiring in June. So, I knew something was up." This seemingly abrupt change for Daryl struck Seija as odd; however, the dementia diagnosis did not arrive for another 8 years.

For a while Charlie said he was in denial about the signs he started to see in his father. Charlie spoke about looking the other way and said, "And I'm assuming like every family and every person's diagnosis is different, but for… for me for the longest time, you could kind of just chalk it up to old age or you could chalk it up to like you know if we were at camp like, 'well, I maybe had one too many beers.' You know, that… I think it's a human element to be able to, yeah, sort of look the other way on certain things, but…" Charlie's admission to being in denial of his father's signs of dementia may suggest that he did not want to believe that his father's health was changing.

When Charlie took his dad Christmas shopping, he noticed more signs of dementia in Daryl. "And so it was just little things like you know, I would take him Christmas shopping or something and I'd have to keep him from wandering off," Charlie said, "But he had, kind of had a propensity for that anyway, so… But it was just, you know, it was just little things that like you always notice about someone's behavior but now amplified." Daryl liked to walk in his early stages of dementia, and now he "wall-walks" as Seija described it. Seija described Daryl's walking habits after a wedding, "It was in the hotel and then they had a like a cocktail time in between and we should have left then as he started to wall-walk. And he'll actually walk along the wall, even where it juts in and out and he's… now you're in a hotel. So, [Charlie] took him up and down the halls a little bit and then he started getting agitated. You just got to go like that's what happened at the [a community program for families and people with dementia] a couple times like it is nice everybody walks him around but after a while you can tell it's not him just wanting to walk, he's ready to get out.” Seija explained that Daryl’s walking was something that occurs when he was upset and ready to leave.

Daryl had difficulties remembering his wife, Seija. One day, when Daryl still lived at home with Seija, he did not recognize her and asked, “What are you doing in my house?” Seija made up a story about how his wife had to go visit her mother and she sent Seija to see if he needed anything. Daryl understood and said, “Well, I'm going to bed now. Kitchen's right there. Help yourself. You want to make or have anything to eat. Thanks for coming by.” Later that evening, Seija climbed into bed with Daryl. Daryl sat up abruptly and said, “Whoa, whoa, whoa, whoa. I'm happily married. Bye.” Even though he did not recognize his wife, his bond with Seija remained, and his commitment to their marriage was clear.

At the long-term care home, sometimes Daryl did not recognize Seija. “Why do you come here all the time?” he asked her, “I see you keep coming back.” He did not recognize her as his wife in the moment, but he remembered that she came to visit often. Sometimes all it took for Daryl to recognize Seija was for her to walk away and come back a minute later. “Hey, when did you get here?” Daryl asked, and the recognition was there again. There were some days when Daryl saw Seija and started to cry, and he hugged her. Daryl did not always recognize family members, but while looking at family photos, Daryl looked carefully at a school photo of his eldest son, Stephen. Although he did not say anything, he smiled at the photo. When his family moved on to look at other photos, Daryl did not let go of the photo. He tried to take the photo with him when Seija took Daryl for a walk.

It was not long after Daryl moved into the long-term care home that Seija decided she wanted to move out of their family home and into an apartment. This was her first time living alone. “I've never had- this apartment I'm in now is the first time in my life I've ever lived by myself. And I'm 70," Seija said. When asked if it was tough living alone, she said, "Yeah, I'm actually kind of liking it a little bit now yeah but um oh yeah, I was really – like I would fall asleep while watching TV. […] So, I would go home and I turn my TV on maybe for that, but I was waking up like 3:30, 4:30 AM in that chair. Yeah. And, um... Yeah, I just didn't like being alone. I still only sleep on a little section of the bed… it's weird…" The adjustment from living with her husband to living alone was difficult for Seija, even in a new environment.

Seija cared for Daryl in the long-term care home, but she also cared for her father and mother who also lived in the same long-term care home. Daryl and Seija's mother both had dementia, and her father had other health issues that required him to live in a long-term care home. Although they live in the same building, Seija described caring for three family members as difficult and stressful. When talking about her situation, Seija said, "Not too many people have a 92-year-old mom and a 94-year-old dad while still taking care of their husband." She did not explain in detail the required care for her family members, but she discussed some of the tasks she completes for her family. "I pick my dad up. And we take him for breakfast at [restaurant]. It's kind of like a family at eight in the morning at [restaurant]. So, we still keep everybody busy. All their medical appointments, whatever. [Daryl]'s [appointments] now are more… um… not taking them out. Like the dental hygienist comes- she comes in, and the foot care comes in which I just make sure I still book all those things." Seija made the time to bring her father for breakfast with his friends and to book additional medical appointments for Daryl. Seija still spends her time and energy maintaining the normal lives of her loved ones living in a long-term care home.

Seija was not alone in caring for her family. Seija, her siblings, and her sons helped care for Daryl and her parents in any way they could, including attending medical appointments, connecting with services that may be available to help, and using technology to keep everyone updated and informed. Seija and her siblings came from various careers, including the mental health field, nursing, and education. Seija said that their careers helped them navigate the health care landscape together and support each other. She said, “you know, and if someone out of the four of us doesn't [know], somebody's always there to say ‘hey, this is how it sounds…’ or ‘I’ll find out for you.’” Their team player attitude showed their care and constant support for one another.

Today, Daryl lives in a long-term care home. He is visited nearly every day by friends and family, including Seija, her siblings, and Charlie’s family. Daryl’s sense of humour persists in his jokes with Seija and mischievous smirks at the nursing staff. Daryl shows affection to his granddaughters, Sophie and Abigail, by holding their hands, laughing, and smiling with them. He continues to enjoy wearing his Toronto Maple Leafs hats and will always agree that this season will be the Leafs lucky year to win the Stanley Cup.

5.4 Making up for lost time: Caroline’s family story in their words[2]

5.4.1 Context

Caroline was 79 years old and living with dementia. She was married to her spouse, Charles (80 years old), for 58 years. They had two daughters, Aurora and Alice. Aurora was the eldest daughter at 57 years old, and Alice was the youngest daughter. Caroline and Charles had six grandchildren: three boys and three girls. Caroline regularly had her nails done and wore

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[2] Some details of Caroline’s story are redacted to protect participants’ privacy and confidentiality.

homemade bracelets to match her nails. Aurora made the bracelets to match Caroline's nails every time Caroline went to the salon.

Family #	Pseudonym (Gender)	Age	Relation to person living with dementia
Family 3	Caroline (Woman)	79	Person living with dementia
	Charles (Man)	80	Spouse
	Aurora (Woman)	57	Eldest daughter
	*Alice (Woman)	N/A	Youngest daughter
	*Hannah (Woman)	27	Eldest granddaughter, primary power of attorney

**Did not participate in interviews or focus groups.*

5.4.2 Early life

Caroline and Charles started dating in 1964. Charles described their first date at a roller-skating rink with smiles and a joke about how they were not good at roller skating, but that meant they got to hold hands. Charles and Caroline enjoyed their honeymoon as newlyweds. At the beach, Caroline wanted to drive on the sand in their car. Unsurprisingly, the car got stuck in the sand. "Well, no, she wanted to drive on the beach with the car, that hard-packed beach," Charles said, "And then we got stuck in the sand and spent the whole afternoon getting the car out […]" This was the first time that Caroline and Charles were stuck on the beach with their car. "And we got stuck. We got stuck twice," Charles explained while showing a photo of the second time they got stuck on the beach, "We got stuck - on our honeymoon; we got stuck in Florida on the beach. Spent the whole day digging our way out."

Caroline worked in the finance and administration field; meanwhile, Charles worked as an engineer. Charles would often travel for work, leaving Caroline alone at home, especially after their daughters had grown up and moved out of their family home. "And that's what's made me realize that when I was working, you know, if I went to Vancouver for five days or seven days, that meant she had to be home alone," Charles said. Being home alone, Caroline developed a reliance on substances and gambling. "So, I mean, I don't fault her for looking for some other kind of thing," Charles explained about Caroline's situation, "You know, it's whether she would come over and spend a day at the casino or something like that. Well, that's probably because I wasn't there."

Caroline's situation was seen by her daughters, too. Caroline's substance use occurred throughout Aurora's life. Aurora reflected on her childhood with her mother's situation. Aurora wondered if her mother smoked and drank from stress. She said, "I think she smoked to deal with the stress of… her and my father arguing because of the drinking. And I mean, not only did she drink, she gambled." As a young woman, Aurora was worried about her mother and described herself as protective of Caroline. Aurora said that as she grew older, she realized the damage that Caroline was doing by her drinking. Despite Aurora's realization, she took on the primary responsibility as a daughter in caring for Caroline in the long-term care home, which illustrated her commitment to caring for her mother.

Moreover, Charles also described Caroline's efforts to quit drinking, including her entrance to rehabilitation programs. Charles reflected on why Caroline may have turned to substances and considered the possibility that the absence of someone at home with her had led her to these behaviours. Charles said, "And she didn't realize the consequences of what was happening, you know." Although Charles outlined challenges that Caroline faced in the past during interviews, Charles also proudly described how Caroline is thriving now in the long-term care home. Charles said that Caroline was actively engaged in conversations with others in the long-term care home, and she was very social. This drastic change from Caroline's reliance on substances to being social and engaged in her long-term care home illustrated her transformation.

Caroline's situation aside, Charles and Aurora reflected on the family vacations and celebrations that they experienced as a family. Photos of the family riding the gondolas in Banff and standing in front of the amusement park rides at Disney World were nice memories they shared together. Photos of birthday parties with cakes filled with candles and many photos of the family's dogs brought smiles to Caroline's face when reviewing photos together.

5.2.3 The dementia journey

Caroline was diagnosed with dementia in 2020. When discussing some of the first signs he saw in Caroline, Charles said, "We're just - she showed certain distinct little changes in her personality, you know, for I guess 3 or 4 years before there was any diagnosis, or we began to suspect something was wrong."

Aurora worked in healthcare, specifically with older adults. Her expertise and experience within the healthcare system did not go unnoticed by the family. "I mean, the single biggest thing is having a family member and, in our case, the daughter being knowledgeable of the process and participating," Charles said about Aurora's involvement. Aurora also agreed that her professional background in healthcare helped the family navigate Caroline's diagnosis and transition into long-term care.

Despite her experience in healthcare, Aurora found it challenging to care for her mother before an official diagnosis of dementia. Caroline often cancelled specialist appointments because she was able to make those decisions for herself. This frustrated Aurora.

Aurora: […] with her having the cognition that she had, she'd always cancel appointments or remove my consent, stuff like that. So it was really hard because some people would see her as being cognitive enough to make a decision. And then when you see her, you know, because you know her that she wasn't capable of keeping those and making those decisions.

Aurora described a frustration with health care professionals who she felt did not understand the extent of Caroline's cognitive challenges. Aurora's frustration with a doctor resulted in the family finding another specialist, which illustrated the challenges some families face in getting a diagnosis in the healthcare system.

Caroline started to forget where she placed items around the house. Aurora said, "And then she was eating things and then hiding things. So we find moldy food hidden in different spots because she'd forget where she put it." Other items were placed where they did not belong, which made it difficult for Charles to find.

Charles: You know, and that was confusing because and it was difficult because you couldn't do things and say, you know, rely on this or rely on that, or I'd go around the house and I couldn't find things because 'where did you put that?' 'I don't know,' you know, you know. And then I'd say, 'Well, I need to get a couple of items. Where's your sewing basket?' No idea. It was in the basement, you know, in the room in the basement.

Aurora said that Caroline started to accuse her of stealing items that she could not find. Caroline eventually started accusing Charles of stealing or hiding items as well. "She would forget where she put things and then she'd start pointing the finger and blaming saying- and it was always me," Aurora said, "I was always trigger. I was the target. That I was coming over to steal. So that would cause an issue between my mother and father because he knew I wasn't taking anything. She would find things when I wasn't around. And then he would say to her, 'but you never apologized. You never say you found it.' And he would do- Or he would say that to her and not long after the accusing of me she would start accusing him."

Charles and Aurora realized that Caroline may need more assistance when she started leaving the house and when people in the neighbourhood started to notice Caroline's different behaviours. "Well… she did [wander] when she was at home, she would wander to [part of town] saying that she's going to do her shopping," Aurora said, "At that time, she was smoking. We could not find her. And that was before she had her Air tag on her necklace. The police had to bring her back home. And they found her in [part of town]." There were also instances where others noticed Caroline's "vulnerability," as Aurora put it. Her concern for her mother's safety in the neighbourhood made Aurora consider moving her into a long-term care home more quickly.

After months of Charles and Aurora "trading" Caroline between their houses to provide respite for one another, the family decided to move Caroline into a long-term care home. Caroline has lived in two long-term care homes since her diagnosis. She only resided in the first long-term care home for about three weeks before her family removed her. Aurora described the recreation program at the first long-term care home as "non-existent" with not enough activities for residents to do. Aurora asked, frustrated. "[…] They were bored. Nothing to do. So what do you do? You're left to your own devices and smoking cigarettes."

After removing Caroline from the first long-term care home, Charles and Aurora cared for Caroline at home. About six months later the family was able to move Caroline into the second long-term care home. Charles and Aurora had very positive things to say about the second long-term care home. Aurora gushed, “And then now that she's in her long-term care facility, you can't say enough about the recreation there. It is amazing! There is always, always something to do. It is like night and day.” Charles compared the two long-term care homes when he said, “You know, [LTCH 1’s] so institutional that it's efficient, but it's not friendly or whatever. Whereas [LTCH 2], yeah, it's everybody's happy, smiling.” Aurora talked about how Caroline adjusted to living in the long-term care home and had been chosen as a mentor for other residents , which provided her with more opportunities to be social.

Relationships constantly change and adapt as time progresses. Caroline’s relationship with Charles was no exception. Aurora reflected on this when describing her parents’ relationship before Caroline’s move into long-term care. Aurora said her parents used to argue, but now that Caroline has moved into a long-term care home, they are back in their newlywed stage. Aurora described their affection for one another, including “smooching” and “cuddling” when they spent time together. Her parents’ renewed infatuation with each other somewhat disturbs Aurora, but it also gives her a sense of relief. “But it's nice that she doesn't remember any of [the arguing]. Yeah, she only remembers the good things.”

Today, Caroline lives in a long-term care home. Charles visits her nearly every day, and Caroline often asks him if he will visit the following day. Caroline has become a mentor in the long-term care home for new residents. Her new leadership role is good for her social skills as she has been tasked to sit with new residents and befriend them. Caroline’s nails are always manicured to perfection, and she has bracelets to match courtesy of Aurora.

5.5 “My mom is an angel:” Evelyn’s family story in their words

5.5.1 Context

Evelyn was 81 years old when she passed away in March 2025. She and her husband James (81 years old) had been married for 60 years. They had two daughters, Nora and Michelle. Nora was the older sister, and she lived in Manitoba with her husband. She had two sons and a granddaughter. Michelle was 55 years old. She lived with her partner in the same city as Evelyn and James. Evelyn lived in a long-term care home for almost 2 years before her passing.

Family #	Pseudonym (Gender)	Age	Relation to person living with dementia
Family 4	*Evelyn (Woman)	81	Person living with dementia
	James (Man)	81	Husband
	*Nora (Woman)	N/A	Eldest daughter
	Michelle (Woman)	55	Youngest daughter

Did not participate in interviews or focus groups.

5.5.2 Early life

Evelyn was born in a small town along the shores of Lake Superior. It was in that small town that Evelyn met James. “I first met her… she was babysitting at a house, and I was there for a party. […] We just started going out after that,” James said about the start of their love story. After getting married in their hometown, Evelyn and James moved to a big city where they had their first daughter, Nora. It was 1967 when they moved to Northwestern Ontario and later had their second daughter, Michelle.

When the family first moved to Northwestern Ontario Evelyn worked at a tree farm. After the tree farm closed, Evelyn became a mobile hairdresser. Meanwhile, James worked as a mechanic and then became a sailor on the Great Lakes. Evelyn enjoyed her job as a hairdresser although she was not always described as an outgoing person. James said, “She was always, I don't say shy, but um… not really outgoing or anything until she realized she had dementia. Then she would talk to people.” Evelyn made many new friends after her dementia diagnosis, and she became an influential leader for women living with dementia.

Michelle described her mother as a person who would help anyone. She said, “[…] we've always been - particularly my mom - but my family has always been the collector of broken souls. So, if anybody needs help or needed a place to stay or whether it was our friends or their friends or family. Family always came to stay with us. So, I think that maybe looking in, people may see our family as supportive to other people as well as to each other. But yeah, I always say my mom is an angel because she always just collected broken souls and took care of them.” The family’s willingness to help others and take care of them when they were in need demonstrates their commitment and character.

As many mothers do, Evelyn ran the family. Her daughter Michelle described James as a leader and a provider, but she described Evelyn as the “runner of the family.” Michelle described her relationship with her mother as the person she would go to whenever she had an issue. She said that her father would simply hand the phone to her mother whenever she called, and that Evelyn was the parent who knew the answers to their questions. Michelle’s reliance on her mother as a mentor and a guide in her life illustrates their close relationship as mother and daughter.

5.5.3 The dementia journey

Evelyn was initially diagnosed with mild cognitive impairment in 2016. A dementia diagnosis followed some years later. The family started noticing different signs that suggested memory loss in the years leading up to the diagnosis. Michelle said that her mother started repeating stories that she had told Michelle before. Michelle told a story about a scheduled mother-daughter shopping date. For a few years in a row, Michelle and Evelyn went Christmas shopping together. However, this particular year, Evelyn made other plans with a friend that same day.

Michelle: I was like, okay, I'm going to take a Friday off in November. We'll go Christmas shopping and we've done it for a handful of years in a row and I came to her place that Friday morning and I said, 'oh, you know, where do you want to go first?' She goes, 'oh, I'm going out for lunch with (friend),' like with her friend. And I was like, '(Friend)? I thought we were going to go shopping today?' And she goes, 'well, no, I have lunch with (friend).' And I went wow, that's unusual because I never take- I rarely take time off work. So, for me to take a day off of work meant this was a big deal. So, I thought, well, that's really odd.

Another instance of Evelyn's memory issues was a story about her last time driving. She was driving home from work as a mobile hairdresser when she got to the last intersection close to their home. "And she didn't know which way to turn," James said, "So, she never drove again." Evelyn's loss of direction prompted the family to ensure she did not drive again for her safety.

Unfortunately, Evelyn’s family is no stranger to dementia. Evelyn’s mother had Alzheimer’s disease, her sisters had dementia, and a close friend of Evelyn had dementia as well. Michelle said that she was afraid for her mother because of Michelle’s experience seeing people living with dementia and what their dementia journey looked like. She said, “It was devastating. I think for about six months I cried every morning when I ran because she doesn't deserve that. And we all know what's going to happen because we've all seen it.”

Evelyn did not let her diagnosis stop her from meeting new people and helping others. At the community program and as part of a local advocacy group, Evelyn opened up and became a more outgoing person. James said, “A lot of women with dementia looked up to her or you know went to her at the program and all that. And she was all bubbly and everything.” She became an advocate for women living with dementia and a leader in the community. Her willingness to help people, her infectious laughter, and her stories about her experiences living with dementia were admired by others.

Leading up to the transition into a long-term care home, James was not able to leave Evelyn home alone, and she was struggling to recognize him. Evelyn had begun to get up at night and sometimes leave the house. Michelle described one instance where Evelyn had wandered two kilometers away from their home and ended up at a hotel. Thankfully, the hotel staff were somehow able to contact James, and he picked her up. Michelle also described situations where Evelyn called in the night saying that she did not know where James was. James was in the house, but she did not recognize him. Michelle then went to their house to reassure her mother and point out the tattoo on James’s arm that Evelyn then recognized him. Michelle said, “So I’d say [to Evelyn], ‘go look at his arm and that’s how you know it’s him.’”

Michelle started to see the stress that taking care of Evelyn had on James. It was when James called Michelle and asked, “Do you remember if I gave your mom her meds or my meds this morning? Because I'm not sure…” that Michelle said, “This can’t go on anymore.” Her father was overwhelmed in caring for her mother and Michelle determined that it was time to make a change. She said, “And that's when I talked to, I think it was one of the workers [at the community program], I don't remember who it was, but I said, ‘Now I'm concerned for both of them. We need to make a change.’ But that's when it accelerated her into transitional care and then [LTCH].” James also reflected on the assistance of the staff at the community program in helping the family make the decision to move Evelyn into a long-term care home. “It's a… even [staff members] when I was making the decision to put her in the home. It was them who helped and had it not been for them, I can't imagine what it would be like.” It took five or six weeks for Evelyn to move from transitional care to a long-term care home.

When reflecting on the family’s dementia journey, Michelle said, “[Dementia] is a heart-wrenching, soul crushing, grief and guilt-ridden journey. […] It is… it's a terrible experience.” She described her pain of watching her mother go through the stages of dementia as “Chinese water torture of grief.” She explained, “Somebody described it as the Chinese water torture of grief. And the other one is you've never felt your heart break more slowly. And so, it's getting more and more painful. But it's riddled with guilt, and it's riddled with grief through the whole journey so far.” Her descriptions paint a picture of what she has felt on this journey. Michelle discussed conversations she had with others about her mother and the time they spent together. She said, “And often people will say to me, ‘Oh, enjoy this time with your mom.’ And I look at them and I just ‘No, I'm not enjoying this time with my mom. That was gone a long time ago. Please don't say that because there is nothing to enjoy.’ She's suffering. She can't communicate.

She doesn't know who we are. She's merely existing. And she's a shell." Michelle's frustration at people who said these comments was palpable. To Michelle, Evelyn was not the woman she once was. Michelle found it difficult for people to understand that her mother had changed so drastically, and she was not the same person anymore.

In March 2025, Evelyn passed away in the long-term care home. Michelle said in an interview before her mother passed that Evelyn was an angel for all of the people that she helped. Her dedication to improving the lives of people living with dementia does not go unrecognized. From helping those in need by bringing them into their family home to advocating for women living with dementia, Evelyn's positive impact on the lives of others lives on. Evelyn's dementia advocacy work continues to be recognized by members of the advocacy group and community program participants.

5.6 Summary

These four family stories illustrated the unique family experiences across their dementia journeys. Each story described the dementia journey from the perspectives of family members and featured a number of people in the family, including husbands, wives, adult children, and grandchildren. Sharing the family narratives was important within this study for providing context for the findings and discussion, but, more importantly, it demonstrated that every family experience with dementia is different.

Chapter 6: Findings

6.1 Introduction

Building on the family stories, the findings centred around the four main themes of this study. Through the four readings required in voice-centred relational approach, four main themes emerged:

1) The meaning of family
2) Maintaining identity
3) Dementia as a disruptor
4) Dementia as a transformer

Despite being separated into different subchapters, these themes are intricately connected. The connections between these themes are described in the findings and linked by the threads of the sensitizing concepts (i.e. roles, relationships, and identities) throughout the findings. Each theme was explored between families and among members of the same family, which provided interpersonal and intrapersonal perspectives. The use of quotations illustrated the family's experiences with dementia and provided context for the findings. Further comparison between the families featured in this study was explored in the discussion section.

6.2 "Family means everything": The meaning of family

We asked participants, "What does family mean to you?" The first theme, the meaning of family, painted a picture of each family and their perspectives on family relationships. This theme explored what was important to each family at a group level and an individual level, which highlighted interpersonal and intrapersonal perspectives of family. This theme explored the family meaning by discussing the relationships participants had with one another, but also touched on their ideas of family identity.

For these families, connection meant many things: physical connections, emotional connections, connections through body language, connections over distance, and other types of connections. Some of these connections did not require verbal exchanges and were represented through a hug, a smile, or a wave in greeting. Some connections were over long distances, like connections with family members who live far away.

Two of the families who participated in this study had family members who had moved to a different city, and they communicated to their family via text, phone calls, and video calls to stay connected. These connections over distance were made in efforts to feel close to the person living with dementia in a long-term care home, to support care partners, and to offer help in any capacity they could. Connecting over Facetime allowed Erika to see her granddaughters even though they lived far away. Calls from a different province allowed Seija to talk to her son, Stephen, twice a day. Stephen checked on Daryl and Seija over Facetime to connect and support his parents whenever possible. Text chains in Daryl's family kept everyone informed about changes, celebrations, and requests for support. Technology played a large role in facilitating connections between family members over distances.

Family members who lived far away came to visit their relatives in the long-term care home. Erika's granddaughters played piano for her in the long-term care home at Christmas time. Janet told a story of when Erika recognized her granddaughter's playing when she heard the music. Janet said these moments of recognition were precious to the family. Evelyn's daughter Nora visited her in the long-term care home. Nora helped feed Evelyn and often gave James and Michelle respite when she came to visit. Michelle described Nora as the "backup" who took charge and organized things when she was able to visit. This brought a sense of relief to James and Michelle and also made them feel supported in their caring. Family members who came to visit, whether they came to see or care for the person living with dementia or to provide support for the care partners, promoted connections within the family. Visits like these strengthened connections and encouraged the family team mentality that many of these families had.

Notably, in Evelyn's family, Michelle described her family relationships by explaining her connections to others.

Michelle: I think when I'm visual so when I think when I think of my family, I think of myself. And then I think of the connecting strings to each of these people. So these are- these people are always a part of me. Their hurts are my hurts. My hurts are their hurts. Their joys are my joys and my joys theirs- And vice versa. So I think that they are always a piece of me. My family is always a piece of me, always connected to me. They're all part of my history, my story, and my future. And I think just that there's always a piece of them in every piece of my story. So I guess they're parts of my puzzle. And they're my go-to and my comfort.

Michelle's description of the interconnected strings of relationships illustrated the shared pieces of connection, like shared joy and hurt. Michelle's visual of the family as the people she was tied to through the experiences they shared illustrated her connections to them. Michelle's connections with her family contributed to her identity, with her family members being seen as pieces of her "puzzle."

Many people think about love as a reason to continue relationships with others. Although it is hard to define love, sometimes people can observe love in its many forms. Love may include caring, sharing moments of joy, or spending time with someone. To define love in any study is difficult; in this study I tried to illustrate what love looked like to these families.

Erika’s family heavily emphasized that love was part of the meaning of family. Janet and Judith both described how love was essential to their family and that family meant unconditional love.

Janet: I think family is, it's essential in our lives. […] But also family means, you know, security, love. […] To sum it up, family is all about caring, giving, and loving, and recognizing that those are essential in your life. […] [Erika] was, and she's always, always given us love without any expectations.

Janet described family as essential because of the security, love, and care that was given to her by her family and that, in turn, she gave love to her family shows the reciprocity of the relationship. This reciprocal relationship between family members showed the mutual connections they had with one another. Erika showed her daughters love without expectations, so her daughters showed love back to their mother as seen in their care for her as she progressed in her dementia journey. Love without expectations was defined as part of unconditional love, which was explored in the meaning of family with Daryl’s family.

Unconditional love means to love someone without expectations, being accepting of them however they are, and committing to loving them regardless of the situation. In Daryl’s family, Daryl’s 11-year-old granddaughter Sophie talked about how unconditional love was part of her family meaning. She said, “[Family means] Someone who cares for you and looks after you and loves you and loves you unconditionally.” Sophie’s reflections on family as someone who cared for her and loved her unconditionally illustrated her relationship with her family. In Daryl’s family, Seija, Charlie, and Sophie referenced unconditional love in their own ways. Seija and Charlie shared that the family was there for each other regardless of any tension between them, and that they “ride or die” for each other as a family. The commitment the family had for each other showed the unconditional love, regardless of whether it was mentioned directly by the family members. In Daryl’s family, unconditional love was crucial to family members and their definition of the meaning of family.

Many of the families featured in this study said that family meant everything. Family members discussed their perspectives on why their family meant everything to them, including the care they showed one another, the challenges one would face without family, and the support and safety they felt with their family. Family members discussed how they were able to rely on their family members, including being there for them when they needed something, prioritizing family members, being reliable and caring when there was an urgent need and working together as a unit.

In Erika’s family, Judith defined family and family members as people she could turn to. She said, “Family - you can always turn to your family if you need them for anything. And they can turn to you. […] Family, to me, should always be number one.” Judith explained that family was her number one priority, which may have been why she felt like she could turn to her family for everything, and they could turn to her, too. Sometimes, prioritizing family came with sacrifices. Between working full-time and caring for Erika, Judith had to manage her household chores and errands on her own time. Judith explained that her weekends were full of grocery shopping, house cleaning, and taking care of Erika to give Janet respite. Despite her busy life, Judith still prioritized family, which demonstrated her commitment to the family unit, and she knew that her family would be there for her if she needed anything as well. A relationship of giving and taking, supporting and being supported, illustrated that family was a group of people with whom participants had a reciprocal relationship. The relationship did not go one way; it was built on mutual support.

In Daryl's family, Seija cared for three people in a long-term care home, with her mother, father, and husband living in the same long-term care home. Despite the stress of caring for three people living in long-term care, Seija still managed to spend time with her grandchildren and help others in need. Seija was dedicated to helping others, and her family was also committed to working together to help others. Seija explained that despite facing challenges in the moment, if a family member needed help, the family stepped in.

Seija: You know doesn't mean that we don't have our moments, yeah, we do but we all pull together when we need to. […] Even extended family as well, you know, like there could be people who might be mad at each other, but if something, if there's an emergency that happens, they're still going to drop everything to go help you.

Daryl's family was ready to jump into action when family members needed assistance, regardless of any disagreements they had in the past. They knew that family was important to them. Being there for one another in a time of need took priority over moments of disagreement which was why the family was able to rely on one another. This family's ability to rely on one another demonstrated that they felt supported and secure in their relationships, and they were unafraid to ask for help when they needed it.

Caroline's family emphasized the importance of relying on each other and working as a unit. When asked what the meaning of family was, Aurora defined family as a complete unit. Aurora said, "Family to me means a complete unit working for each other. Just it's like a welloiled machine keeping things moving. Being there to support each other and rely on each other. Just having that one complete unit." For Aurora, "a complete unit" included Caroline and Charles, and others involved in care, like her niece, Hannah and Aurora's son and daughter. Whether "care" involved visits to long-term care or booking appointments, they worked together as a team to help care for Caroline. Aurora referred to those she considered family as those involved in Caroline's care, but this question may have been answered differently in a different context than this study. Aurora's meaning of family involved the people she relied on, and it was possible that the people she relied on the most were those involved in Caroline's care. Similarly, Charles explained that family members were people he could ask things of. He said, "Well, it didn't - it just means people you knew. People you could ask things of earlier on, but right now, it's a lot different." He said that in the past, he considered family to be the people he could ask for things from and rely on. Now there were fewer people he could depend on. From Charles' description, the family unit has been smaller in recent years than in the past because people have passed away. He referenced his parents, Caroline's parents, and siblings as people he could rely on, but now that they have passed away, there are fewer people he can count on to be there for them. This also contributed to the idea of transformation because the meaning of family changed due to transformation in the family, including family members passing, moving away, or moving into a long-term care home.

The families featured in this study were going through their unique dementia journeys, which sometimes required support. Reaching out for help and relying on others was a symbol of strength. For many of the care partners, it was difficult to admit when they needed help, especially with the responsibility of caring for a loved one. Charlie discussed this when talking about how proud he was of his mother for admitting she needed to move Daryl into a long-term care home.

Charlie: I think I'm very thankful that [Seija]… recognized that… You know, I see like some of my friends who have gone through similar experiences with a parent you know where their parent who didn't receive the diagnosis is almost like, “well, you know, this is till death do us part. So, no one's going to help and I'm not going to put them at home.” And I'm very proud of my mother for being able to look past that almost prideful element and is that like it's not sustainable to provide full-time care for a person like that. So, once we, you know, he’s now… he's safe and well cared for.

To Charlie, seeing his mother recognize that she was not able to take care of Daryl was a show of strength. Charlie supported Seija in her decision to move Daryl into a long-term care home. He knew that she was able to rely on the support of long-term care staff to keep Daryl safe and cared for. The transition from caring for a relative at home to relying on the staff at a long-term care home to care for them was difficult, but this family recognized when they needed help, acted on it, and supported each other through it.

In Erika’s family, Judith shared the importance of family by saying, “I think family means everything, right? It's the most important thing, is family being together and being there for each other, taking care of each other.” Judith’s perspective of family being there for each other illustrated the expectations that she had for family to take care of one another. This may suggest that there was a duty to care for one another when people are part of a family. Additionally, Janet described her responsibility in caring for her mother while she lived in a long-term care home, which also illustrated a sense of duty to care for family members.

In Daryl’s family, Seija and Charlie explained that family meant everything to them, regardless of the situation.

Seija: Family is everything to me for sure. Even in the good and the bad. […] I think of that to sum it up, it means everything. I think it would be tough without it. I know it would be for me.

Seija’s idea of “everything’ involved the good parts and bad parts of relationships with family members. Similarly, Charlie also said that family is everything to him: “I mean, family is everything, right? Like… It means… support and safety and love and… [*long pause*] You know there's… there's like a like there's that ride or die element like you can say that about people, but with our family like people really mean it.” Charlie’s term “ride or die” referred to the family’s ongoing support for one another and loyalty to the family, like committing to one another and relying on family members for help when they needed it. Charlie’s idea of family as “everything” covered feelings of support, safety, and love, which indicated what was important in being part of a family to Charlie. Charlie’s feelings of security and belonging in the family showed that the family was a constant presence in his life. He also discussed what he called the “ride or die element.” Charlie and Seija considered “the good and the bad” when they discussed how family meant everything to them.

Overall, *the meaning of family* covered the good, the bad, and the ugly of what families experience with dementia in the picture. It explored self-made definitions of what family looked like and the values that these families put on their familial relationships. Family members have been there when things became difficult, when relatives became vulnerable, and when there was conflict in the family. This theme also discussed the reliance family members had on one another for support, especially with dementia in the picture. Support included visiting, participating in care, and being there to mentally and emotionally support each other in times of need. Shared values between families included the connections they shared with family members, their reliance on one another for support and care, and their love for one another. Exploring these values demonstrated what family identity looked like in these families by putting emphasis on what mattered to them at an individual level and at a group level, a topic that was further explored in the theme *maintaining identity.* This theme also has significant connections with the theme *dementia as a disruptor* and *dementia as a transformer* because of the ties to the disrupted and transformed roles and relationships.

6.3 Maintaining identity

The second theme, *maintaining identity,* explored how identity was maintained for the person living with dementia and the role of the family as a unit in maintaining identity. Roles, and intrapersonal and interpersonal relationships played large parts in maintaining identity. There was the potential for many interesting subthemes regarding maintaining identity. However, this study focused on identity through roles, music, and fashion.

6.3.1 Identity through roles

Maintaining identity through roles explored how family members maintained the person living with dementia's dignity, autonomy, and identity through interactions and relationships. This subtheme illustrated that the person living with dementia still maintained their identity regardless of their change in cognition. It is true that the person living with dementia changes in many ways; however, they still have the fundamental parts of their identities that make them unique. The roles that they carried throughout their lives are still present regardless of their stage of dementia, and sometimes new roles and identities emerge with dementia.

In Erika’s family, Judith described the feelings of loss that their family experienced but also said that there were parts of Erika that were there from before her dementia diagnosis.

Judith: And I think it was hard for us to deal with the loss. Like, you know, because we really did lose the mother that we knew, and now she's a, you know, completely different mother now. Right? […] A long grieving process. Like, you know, a little bit of her is still in there that we know and, you know, sometimes she'll still like try to take care of me or make sure I'm dressed properly and stuff like that, right?

The Erika that Janet and Judith knew as children was still present in the Erika living with dementia. The mother who dressed them properly as children continued to do that with her adult daughters. For this family, Erika’s dementia progressed rather slowly over the years, and they were grieving for a long time because of it. Seeing parts of their mother change was difficult for Judith because she saw how dementia changed Erika from the mother she knew. Judith then described actions that have not changed with Erika’s dementia, including how Erika continued to call Judith “her baby.” Judith said, “I am the youngest, so I was always her baby, right. And she-she always babied me. It doesn't matter what my age is. Even now, she babies me, right? And she still tells people this is my baby.” Erika was still a nurturing mother to Judith. Judith described Erika’s actions like fixing Judith’s clothes, brushing off dirt from her pants, and feeding Judith when she visited. These nurturing, motherly actions illustrated that Erika still saw that her children needed care, and she fulfilled that role in a capacity that she was capable of. Part of Erika’s identity was being a mother, and by caring for her daughters, she maintained that part of her identity. Another part of Erika’s identity was as a homemaker. Her role of caring for the house was present throughout her life, including through her dementia journey.

Janet: I was saying that when we bring her to our house, the first thing she does, hey mom, you go right to my kitchen, grabs a tea towel because I make sure that there's dishes in the sink, and she starts drying. It's just in tune with her. Like it's just, she's a homemaker, right?

Judith: Or she'll start folding your clothes. I always have a basket there.

Janet and Judith provided Erika with activities that she did in the past, like dishes and laundry, in order to maintain Erika's identity as a homemaker. These routines and chores provided purpose and achievement, which was important for maintaining identity. Erika's identity as a homemaker was maintained through chores that provided purpose and fulfilled the role she had throughout her life.

Maintaining identity through roles focused on how families maintained the identity of their person living with dementia by providing activities they had done in the past. Encouraging these activities and engaging them in previously enjoyed activities connected them to their identity.

6.3.2 Identity through music

The families featured in this study had a connection to music one way or another. From casual music enjoyers to regular concert attendees, these families enjoyed music and embraced the connection their person living with dementia had with music. Janet described Erika's connection with music and her enjoyment of playing piano.

Janet: We take the elevator to the third floor, fourth floor, but she just loves going to the third floor because then we plunk on the piano. Yeah, you know, mom is not making any sense on the piano, but its fun watching her because she has a really good ear for music. Even though she doesn't know how to play the piano she actually can follow the rhythm with the keys. […] So, she's not erratic, like she'll follow it down and follow it up, so it makes a melody. So, it's really quite interesting. So, I let her just go wild on either piano on the third floor.

Although Erika never learned how to play piano, Janet said she always had an ear for music. Janet continued to let Erika have fun and enjoy herself on the piano because Janet knew of Erika's love for music. Janet told stories of how Erika loved to dance with her friends in the squares of Eastern Europe. Erika's musicality was part of her identity, and part of her identity that her family continued to maintain with dementia in the picture.

Similarly, Caroline also enjoyed music and followed the beat of the music played by the bands performing in a long-term care home. Charles spoke about Caroline's love for music and her engagement with music.

Charles: Yeah. If you watch her when they have a music group going like that, you know, she can keep beat to the music very well. You know, it's yeah, she enjoys the music, but then when I take her in the car, she's in the car like she's conducting an orchestra. You know, it's – but that's fine. That's fine. You gotta have something.

As Charles described, Caroline liked listening to live music and started conducting the band when music was playing. Her engagement with music was related to part of her identity because she found purpose and enjoyment in it. Charles and Aurora did not mention Caroline's engagement with music before her dementia diagnosis, so this part of her identity may be new and emerging. Caroline may be discovering new parts of her identity. This demonstrates that the journey of self-discovery and new identities is still present in people living with dementia.

Daryl and Charlie shared a special connection over music. The family said that music was important to Daryl. Charlie was a musician, and Daryl and Charlie used to attend concerts together. Seija described a moment of recognition with Daryl after hearing a song Charlie had created with a friend.

Seija: [Charlie] is a musician. So, I played a Christmas song that [Charlie] did with another friend that's on the radio all the time, so that you know what I'll let [Daryl] hear that and he um… He smiled and he said, [nickname for Charlie]. You know, so he recognizes and then sometimes he doesn't at all.

Daryl's connection with music and recognition of Charlie's song demonstrated that people living with dementia maintain the fundamental parts of their identities. Daryl's love for music never faded, even when he did not recognize Charlie's song, because being a lover of music was part of his identity for so long.

Identity through music showed the connections people had through music and how it contributed to their identities throughout their lives, even into a dementia diagnosis. The love, passion, and joy people living with dementia felt through music was, and will likely continue to be, part of their identity.

6.3.3 Identity through fashion

Dressing well and looking good were always important to the people living with dementia in this study. Families helped maintain identity through fashion. Whether fashion included clothing, manicures, jewellery, or hair appointments, families ensured that their loved ones were looking and feeling their best. Living in a long-term care home did not stop families from maintaining their loved one's identities through fashion.

Erika's love for clothes began at a young age back in Europe. Her shared memories with Janet about her priorities in looking for dresses and shoes over purchasing food for herself illustrated her passion for fashion. Janet said, "[Erika] says, 'honey, like I would have, we (girlfriend and Erika) would get paid. And the first thing we would do is buy a dress and shoes. And we might have enough for one loaf of bread.'" Because of Erika's well-known love for clothing, Janet and Judith made sure to dress Erika well by providing clothes in the long-term care home that she would enjoy. Additionally, Erika's family ensured that Erika's opinions on fashion and clothing were heard by asking questions for her feedback.

Janet: She loves clothes. So, if I bring in something new, she'll go touching. She goes, "love it." And so, then I'll branch off on that and say, "so, what do you think about the colour, mom? Do you think the colour is okay for me? Should I have changed the color?" So, I'm just trying to get that mother-daughter conversation going back where my mom has… I've relied on my mom on a lot of things, to support me in decisions.

Janet tried to bring back the conversations she used to have with her mother. Conversations about Erika's opinions and thoughts on Janet's decisions were important in their mother-daughter relationship. She said that she often relied on her mother for guidance in life, and although she could not guide Janet as much, Janet still tried to have those conversations with her mother. Janet made sure that Erika knew that her opinions were valued and sought after, which helped maintain Erika's identity as a lover of fashion.

In Daryl's family, Seija bought clothes for Daryl while he lived in a long-term care home. Despite what people have suggested, Seija continued to buy items that Daryl would have picked out for himself.

Seija: [Buying clothes for Daryl] So, his clothes, like somebody said, oh, don't spend a lot of money on like he doesn't wear regular pants anymore, but he wears like you know like I go to [clothing store]. Because I think they said, oh, a commercial washing machine after a while like it's hard on it. So just get cheap stuff from somewhere else. I said, no, no, I'm going to still buy things that I think that he would like.

Seija maintained Daryl's identity by purchasing things he would have chosen for himself. When asked by others why she bothered purchasing more expensive, high-quality clothes, she said, "He's not really aware of that, but I am. […] I want to make sure he still feels good and looks good." Seija's determination to make Daryl look good while living in a long-term care home illustrated her efforts to maintain Daryl's dignity by doing what she knew he would choose for himself. After being married for 48 years, Seija knew Daryl. She knew his preferences and what he would choose for himself if he could go shopping with her. Seija maintained Daryl's dignity and identity through fashion.

Caroline's daughter Aurora helped her maintain her identity of being a lover of fashion and a well-put together lady by ensuring that she had her nails done and was always dressed well.

Aurora: Only because she's always had her nails done and that's one of her last luxuries. […] And then I make all her bracelets to go match with her nails. […] Because it's hard to find nails, not nails, hard to find matching bracelets anywhere without paying an arm and a leg.

Aurora ensured that Caroline could access some of “her last luxuries,” such as getting a manicure every few weeks. Aurora also put in the time and effort to hand bead bracelets that match Caroline’s nails. Her jewellery and manicure always matched, and this coordination of colours took time. Regardless, Aurora found the time to maintain her mother’s identity while she lived in a long-term care home. Aurora’s maintenance of Caroline’s identity went beyond the jewellery and manicures. Aurora knew Caroline. She knew what Caroline would want for herself based on what Caroline enjoyed in the past. She knew what Caroline would choose if given the opportunity and made those decisions for herself, thereby maintaining her dignity and identity.

These families put in the time and effort to ensure that their person living with dementia maintained their dignity and identity throughout their dementia journeys. Asking for opinions on fashion, choosing clothes they would have picked for themselves, and ensuring appointments they would have enjoyed are continued illustrated some of the ways families maintained the person living with dementia’s identity through fashion.

The theme *of maintaining identity explored how identity was maintained for the person living with dementia and the* role of the family in maintaining identity. The three subthemes illustrated the ways in which families maintain dignity, autonomy, and identity through roles, music, and fashion. Clearly seen in these subthemes was the knowledge that family members had of their person living with dementia. Knowing the person was important to making decisions for the person living with dementia and ensuring that identity and dignity were maintained throughout their lives.

6.4 Dementia as a disruptor

The third theme, dementia as a disruptor, illustrated the impact that dementia had on the family as a unit. There were positive impacts, such as stronger relationships and newfound appreciation for family members, and negative impacts, such as challenges between family members or changes in the lives they had pictured for their loved ones. Subthemes included *the transition into a long-term care home, "This is not how life was supposed to go…": Imagined life vs. lived reality, realization disrupting the future, the changed person, and grief.* These subthemes explored how dementia disrupted what families pictured for their lives and the lives of the person living with dementia. Stories about their imagined futures in retirement and older adulthood were discussed with family members. Adult children also had realizations for themselves and what their futures may look like. People living with dementia changed in their preferences and attitudes, which were difficult for many family members to navigate. Finally, feelings of loss and grief experienced by spouses and adult children were described.

6.4.1 The transition into a long-term care home

The transition from living in the community to living in a long-term care home can be challenging for the person living with dementia and their family members. The families in this study experienced a disruption of their ways of living after the transition of the person living with dementia into a long-term care home. Stories about resisting care, anger and frustration, and the eventual acceptance of the living situation were discussed in interviews. The subtheme *the transition into a long-term care home* explored the challenges families faced while moving their loved one into a long-term care home, the disruption this transition caused, and the transformations families began to see during the transition.

Erika moved from living in the community with her husband, Danny, to a condominium when Danny went to a long-term care home due to his health conditions. After Danny passed away and Erika was diagnosed with dementia, Erika's family was concerned for her safety while she was living alone in the condominium. As a result, Erika's family moved her into an assisted living home. After some situations where Erika walked away from the assisted living home, the family moved her into a long-term care home. There were multiple transitions in Erika's journey which made Erika feel frustrated, as Janet explained:

> So now the journey becomes where there's more anger because we remove her from her condo to assisted living in [assisted living home] and she doesn't like [assisted living home] at all. So, she's resisting that care. And at the same time, she's deteriorating, right? So, she's angry, but she's deteriorating and her memory's getting worse. So, the care on many levels- you're dealing with anger and fear.

There were multiple transitions for Erika and these transitions came with new environments, new people, and the loss of her belongings as her living space got smaller. Meanwhile, Erika's dementia continued to progress. Erika's frustration and anger at the decisions made for her were difficult for her daughters to deal with. Janet and Judith explained that Erika's walking continued in the long-term care home, and she tried to leave the home. Judith said that Erika wore her coat and gathered her things in preparation to leave for months after the move into the long-term care home. The transition into a long-term care home disrupted and transformed the family relationships because Janet and Judith saw a side of their mother that they had never seen before. Erika had always been kind, gentle, and nurturing to her family, but the transition into a long-term care home in addition to the progression of dementia, transformed Erika into someone Janet and Judith were unfamiliar with.

Daryl’s family experienced similar challenges when they were transitioning Daryl into a long-term care home. Seija and Charlie faced Daryl’s anger at moving into a long-term care home and unkind words were yelled at them.

Seija: The first day when we admitted him was awful. [Charlie] will probably talk to you about that. It was devastating for [Charlie] because he… He said, you know, “you're not my son anymore.” And “it's like I'm a dog and you've taken me to the vet” you know. And that was unusual to have seen that kind of clarity of anything with him.

Daryl’s anger toward the family for moving him into a long-term care home was challenging for Seija and Charlie to deal with. It was difficult for Charlie to be yelled at by his father when Charlie was trying to do what was best for Daryl and what was best for his family. Charlie explained how he was proud of Seija for realizing that she could not provide full-time care for Daryl and decided to move him into a long-term care home. Charlie said that he was grateful that Seija looked past the prideful element of caring for a spouse with dementia and realized it was not sustainable for her to continue caring full-time. Although this transition was difficult for the family and resulted in anger and frustration from Daryl, Charlie recognized that Seija’s health was also important. He understood how challenging it would have been if Daryl remained at home with Seija.

The transition into a long-term care home was not only challenging, but it disrupted and transformed the family member’s roles in care. For Seija, she was taking care of Daryl at home full-time, but the role transformed to taking care of Daryl with the help of the long-term care home staff when Daryl transitioned into a long-term care home. Her role, and part of her identity, as a care partner shifted locations, but the role was still a major part of her life. A disruption for

Charlie was that his father was no longer physically in the household, and Charlie transformed to take over the paternal role in the house with his brother, Stephen. Charlie said that he and his brother started to "fill the void" that was left by their father's dementia. Both sons helped Seija with decision making, but Charlie also described his role as the voice of reason. Charlie described Stephen's role was as the "enforcer" where Stephen would suggest solutions for the family and help execute them. The shifting roles of the sons in the absence of their father illustrated the disruption of the family after the transition into a long-term care home, as well as the transformation families experienced because of dementia.

In Caroline's family, Charles and Aurora told the story of Caroline's first transition and removal from a long-term care home. There were challenges in the first long-term care home, including difficulties with other residents, issues with staff, and the lack of programming offered to the residents. After three weeks of living in the first home, Aurora removed Caroline from the long-term care home, and Caroline moved back home. Caroline moved between Aurora's house and Charles' house for six months before she was able to move into the second long-term care home. Caroline, Charles, and Aurora were much more content with the second facility because of the staff working there and the programming offered to residents. Charles described Caroline's experience there and her acceptance of her living accommodations.

Charles: Well, that's what it is, because she… she hasn't - I don't think she would have an awareness of a long term. She's content. I find the biggest thing knowing her for all those years, I have found it absolutely amazing that she has accepted where she is and how she, you know, she at one time I see other people there, they're crying. They want to go home. They want to do this. And that's not her. She just

> has accepted what's there and I don't know why. Whether she, you know, for her own good or not, I don't know.

Charles' comparison of what other people have experienced, like crying and wanting to leave the home, to Caroline's acceptance of where she lived showed her transformation. Caroline participated in programming, enjoyed listening to live music, and became a mentor for other residents in the home. Caroline transformed within the long-term care home. It greatly benefited her social life and reduced Charles and Aurora's stress about the transition. Caroline's transformation after her transition into a long-term care home demonstrated that people living with dementia are able to transform and adapt throughout their dementia journey.

The transition into a long-term care home was difficult for these families and they experienced a disruption and transformation of roles, relationships and identities. Feelings of stress, frustration, anger, and acceptance arose, but sometimes the transition was necessary for the safety of the person living with dementia and the mental well-being of the family members. The experiences of the families featured in this study explored journeys of anger to contentment, and frustration to acceptance. These may not be universal experiences; however, transitional periods in life can raise various emotions, and the experiences of these families illustrated the challenges that may arise.

6.4.2 "This is not how life was supposed to go…": Imagined life vs. lived reality

The families featured in this study, much like many people, imagined what their lives would be like as they aged. In this study, dementia disrupted the family's idea of what life was supposed to look like. Dreams of retirement, ideas of what grandparenthood would look like, and living to old age together were some of the changes people had to adapt to. The subtheme *"This* *is not how life was supposed to go…"* explored the changes that families had to adapt to because of dementia disrupting their imagined lives.

In Caroline's family, Aurora discussed her change in roles from daughter to care partner and how dementia impacted the family's imagined life. Although Aurora admitted that her experience in health care has helped her transition from her identity as a daughter to a care partner, she also reflected on this experience in comparison to what she thought life was going to be like for the family unit.

Aurora: I've completely gone from daughter to care giver. Not something I was thinking would happen in my life, like I've said to my father several times, "this is not how life was supposed to go. This was not the plan that we had in mind." And… It's frustrating, but what can you do? You can't change [the situation]. So you just deal with it, right? […] I think we like, well, for me, I have dealt with the part knowing that this is not how it was supposed to be. And I dealt with that. So we're dealing with what it is.

The family's life plans and what they imagined for their lives were changed because of Caroline's diagnosis. Aurora's frustration turned to resignation when she said, "So, you just deal with it, right?" Although dementia disrupted Aurora's imagined life, she was transformed by accepting the situation. She accepted her mother's dementia and continued to move forward as a family. This quotation also contributed to the theme *dementia as a transformer* by exploring Aurora's changing role from daughter to care partner.

Charles explained that he had imagined what retirement would look like for him and Caroline, but things have changed since Caroline's move into a long-term care home. Charles' imagined life for him and Caroline in their retirement involved travelling and doing things that they dreamed of together. The lived reality was that Caroline's dementia diagnosis disrupted the plans they had together. Charles acknowledged that Caroline lived in a long-term care home and that she was not moving back home with him to experience their imagined life together. Instead of focusing on the imagined life, Charles realized that life was not going to go back to how it was before dementia and embraced the lived reality of the situation. He chose to live in the present moment by visiting Caroline in the long-term care home, looking at family photo albums, and watching the musical performances together. Charles's acknowledgement of this new reality and decision to let go and move forward illustrated his perseverance as he navigated this new experience.

In Evelyn's family, Michelle explained that people told her to "enjoy" being with her mother, which Michelle found difficult because of the stage of dementia Evelyn was in. Michelle shared her frustration with people's comments about what she and her family were going through.

Michelle: And often people will say to me, "Oh, enjoy this time with your mom." And I look at them and I just "No, I'm not enjoying this time with my mom. That was gone a long time ago. Please don't say that because there is nothing to enjoy." She's suffering. She can't communicate. She doesn't know who we are. She's merely existing. And she's a shell.

Outsiders offered advice to Michelle on what they thought she should be doing with her mother living with dementia. They had an imagined life of Michelle enjoying every moment with her mother living with dementia. This was a skewed idea from the lived reality that Michelle had of seeing her mother "suffering" with dementia. Dementia disrupted the Evelyn that Michelle knew and the relationship they previously had. Even though Michelle described Evelyn as “a shell,” Michelle’s actions toward her mother showed that she believed otherwise. Michelle deeply cared for her mother and treated her with dignity. Michelle imagined her relationship with her mother as it was before dementia, but the reality of the situation was that dementia disrupted the relationship they had before. People outside of the family had an imagined life of what it meant to care for a parent living with dementia that was vastly different from the lived reality of family members.

Seija also experienced a rift between her imagined life with Daryl and her lived reality. In her interview, Seija described her imagined life in retirement with Daryl, which included travel plans, continuing to live in their family home, and spending time with their grandchildren. However, after Daryl did not recognize Seija in their family home before bed, Seija moved to sleep in the guest bedroom. Seija explained, “That was the last time that I slept in my own room because… […] Because you never know when the person woke up in the night or whatever, like you have to know who you are and he's in the wrong house and… Yeah, that was hard.” Seija faced a new reality: she and Daryl were not able to continue living in their family home as a couple. Eventually, Daryl moved into a long-term care home, and Seija moved out of their family home and into an apartment. Seija’s lived reality was one where she and Daryl no longer lived together. They were not able to travel like she imagined. The time spent with their grandchildren looked different than Seija imagined because she attended her grandchildren’s sports and activities without Daryl. Dementia disrupted Seija’s imagined life for her and Daryl.

The realization that dementia was quickly becoming such an integral part of their life was frightening for some of the adult children featured in this study. Adult children shared their fears and realizations about their parent’s dementia, as well as potentially having dementia later in life themselves. Daryl’s son Charlie shared his sudden realizations of dementia after his father was diagnosed.

Charlie: [Dementia is] in my family but you don't realize what that means until you're actually seeing it. And you're confronted with the fact that like, holy fuck, like this could be me, you know? And then you look and you're like, it’s not as much time as I thought. Um… And not, I mean, that's not like front and center because you're still all like simultaneously dealing with a parent who's going through it. But yeah, I'm not sure if that's been mentioned at all, but I feel like it must be because I've had this conversation with other friends whose parents have had dementia and Alzheimer's too. Yeah, I think it just kind of makes you realize how short the time you got.

Charlie’s reflections on mortality were initiated by his fears accompanying Daryl’s dementia diagnosis. His reflections were a direct result of the diagnosis and the awareness that he could be diagnosed with dementia later in life as well. Charlie quickly realized with his father’s diagnosis that life is finite. Dementia had disrupted Charlie’s perceptions of life by making him realize his father’s mortality and consequently, his own.

In Evelyn’s family, Michelle immediately made changes to her lifestyle when her mother was diagnosed with dementia. She explained that dementia had always been on her mind since her grandmother and aunts had dementia. Once Evelyn was diagnosed, Michelle changed her health habits, including diet and exercise. Michelle admitted that part of her identity became dementia prevention. She said, “And so I think part of my identity became just everything about Alzheimer's prevention. And I think that that became what I did on a regular basis. That's all I did. That's all I did was eat, sleep, literally breathe, and live just… That became my identity in the short term. But overall, so that's one piece. […] But there was- so that was what changed my identity right away. I became fearful.” Her partner made sure to ground Michelle by reminding her to live for today. Michelle’s reflections on how her identity changed after her mother’s diagnosis to focusing on preventing dementia in her future illustrated the realization she experienced because of dementia. Her immediate changes to her health habits in a frantic scramble to prevent dementia were a result of her fear. Not only was Michelle afraid for herself, but she was also afraid for her mother. The family’s close encounters with dementia and the stages of dementia made Michelle scared for her mother when Evelyn was first diagnosed.

Michelle: [The diagnosis] was devastating. I think for about six months, I cried every morning when I ran because she doesn't deserve that. […] So I knew I was afraid for my mom.

Michelle’s experiences seeing many of the women in her family diagnosed with dementia made her fearful of what was to come. Despite her fears for herself and her mother, Michelle reminded herself that being fearful of the future was not beneficial. She said she reminded herself to “live today” like her partner suggested. Dementia had disrupted Michelle’s perspectives on life and how she lived it on a daily basis. Her fears for the future had changed her activities before she realized that living for today was more valuable than being afraid of what might happen in the future.

The family members described their challenges with facing a new reality that was not at all what they had imagined because of dementia. Dementia disrupted participants’ ideas for the future. Their realizations, fears, and actions illustrated the uncertainty of life and the fear of being diagnosed with dementia themselves. The imagined lives painted a picture of an idealized, happy future as a family. Unfortunately, that was not the lived reality experienced by these families. Despite the reality they faced, the families continued to persevere and move forward in their dementia journey.

6.4.3 The changed person

With dementia, people can change in personality, behaviours, habits, likes and dislikes, and roles for example. This can be challenging for family members to deal with or understand. For example, a parent living with dementia that the adult child has known for decades has changed something fundamentally unique to their personality, like their love for a certain sport or band. This can be jarring for the family members and result in feelings of unfamiliarity and grief over losing a part of that person. In this study, family members discussed how their family members living with dementia changed.

Erika's daughter, Janet, discussed her experience of seeing her mother change with dementia.

Janet: And if I could, you know, I could tell, you know, I sit down with a person at the early stages they're still going to have their own journey. I can tell them what they're going to, what they may go through. I can tell them what they may feel at times. How there's going to be lots of episodes of them breaking down because they're watching someone deteriorates so quickly or deteriorate to a person that they're not anymore, like the ones that they, you know, the person that they first knew all their life. So can you imagine that a happy, nurturing, loving parent changing over months to a person that you don't even want to be around anymore. Until you know, they change into the stages that are inevitably forthcoming.

Janet explained that as her mother's dementia progressed, she saw her mother change from Janet's nurturing, loving mother to someone who was emotionally responsive. For a period of time during her dementia journey, Erika was angry toward her daughters, including moments when she would swear, yell, and hit them. Janet's reflections on how dementia impacted her mother's personality, from a happy and nurturing mother, illustrated dementia as a disruptor of the person Janet once knew. The feelings of unfamiliarity with who her mother had become with dementia were complicated for Janet to deal with. These feelings were new to Janet and illustrated how dementia disrupted the person Erika once was to Janet.

Daryl had always been a hockey fan and a lover of music. His son Charlie emphasized the importance of these things in Daryl's early life. Evidence of Daryl's love for sports and music was seen in family photo albums featuring Daryl at hockey games, golf courses, and concerts. However, with Daryl's dementia, he did not show much interest in the things that once brought him entertainment and joy. Charlie expressed how hockey and music were not something he could look forward to or interest Daryl in anymore.

Charlie: [Hockey] was really important to us and to him. And you know, music was another big thing. He and I used to go to concerts together all the time, but certainly I could never dream of doing anything like that again.

Similarly, Seija discussed how Daryl's likes and dislikes had changed.

Seija: The person that you've been with for so many years isn't that person anymore. And that's really difficult. Even their likes and dislikes with food and TV shows or anything just- just changed. Although [Daryl] still loves hockey. He does, but he doesn't talk about it like he used to.

It was difficult for Seija and Charlie to deal with these changes. The person who liked watching hockey, enjoyed listening to music, and whose preferences they knew had changed with dementia. The ways that family members were able to interact with Daryl about his previously enjoyed activities also changed. Daryl's reactions to music or hockey may have changed with dementia, but Daryl may still enjoy those things and not be able to express himself the way that he had previously. Regardless, dementia changed Daryl, and Seija and Charlie felt unfamiliar with the changed person before them. Dementia disrupted their knowledge of some of Daryl's preferences, resulting in their feelings of unfamiliarity.

The changed person illustrates the family member's feelings of unfamiliarity with their loved one as the person progresses in their dementia journey. Dementia disrupted the person living with dementia that they knew before dementia. Although it was difficult for family members to adapt to meet the needs of a person whose preferences and behaviours changed from who they once knew, families made efforts to understand and adjust to a changing person.

6.4.4 Grief

People often discuss feelings of grief, loss, and mourning when discussing their dementia journey and this study was no different. Families discussed feelings of grief with the dementia diagnosis and the dementia journey. The emotional journeys that the families experienced were difficult and caused emotional pain. In Evelyn's family, Michelle described her feelings of grief in the dementia journey so far.

Michelle: But it's uh it's- Somebody described it as the Chinese water torture of grief. And the other one is you've never felt your heart break more slowly. And so, it's

> getting more and more painful. But it's riddled with guilt, and it's riddled with grief through the whole journey so far.

Michelle compared her feelings of grief through the dementia journey to torture and heartbreak. This comparison paints a picture of what families go through when watching their loved one's dementia journey. Michelle's feelings of hurt and pain as she watched her mother's dementia progress illustrated the journey's challenges. Despite this, Michelle loyally went to the long-term care home every day to visit and feed Evelyn.

Finding the support required to handle grief and loss can be difficult. Between managing caring for a person living with dementia and managing their mental and physical health, care partners sometimes struggled with finding the time and energy to reach out for help. Thankfully, Seija had many friends within the advocacy group who helped support her through everything dementia has disrupted.

> Seija: [Friends are] just really good like- so that's the really feel-good part of those types of relationships, which helped me kind of get out of that… It's not that I'm not grieving all the time, but my grieving… I'm handling a little bit different now. I know where to connect myself when I need to do that.

Seija connected with supports that helped her manage her grief. Her friends were mostly care partners who had experienced caring for a person living with dementia, whether their partner lived in a long-term care home or had passed on. Everyone's journey was unique, but Seija said that their feelings of connection, despite their different experiences, showed how much they understood each other.

The theme *dementia as a disruptor* explored the many ways dementia disrupted the family, including the transition into a long-term care home, lived vs. imagined realities, adapting to a changed person, and feelings of grief. Even though dementia disrupted these families in many ways, dementia caused a transformation, as explored in the theme *dementia as a transformer.*

6.5 Dementia as a transformer

Receiving a dementia diagnosis resulted in the transformation of the person living with dementia and the family as a whole. The fourth and final theme, *dementia as a transformer,* explored how a dementia diagnosis transformed the family, and explored the transformed roles, relationships, and identities of family members and the family as a unit. Subthemes included *growing because of dementia*, *changing relationships*, and *transformed perspectives*. The subtheme *changing relationships* explored spousal relationships, parent-child relationships, and intergenerational relationships.

6.5.1 "That's all new to me": Growing because of dementia

With the diagnosis of any disease, individuals may feel the need to learn about the causes, symptoms, and what to expect as the disease progresses. For these families, dementia was no different than other diagnoses. Family members looked to books, the internet, support groups, and specialists to guide them in their dementia journey. They emphasized learning about dementia, learning how to take care of someone living with dementia, and understanding the changing person before them. *Growing because of dementia* focused on family's experiences learning about dementia and their growth through their dementia journey.

In Erika’s family, Janet and Judith had to learn about dementia and, over time, started to understand Erika’s behaviours. Janet described her experience of growing because of her mother’s dementia and what she learned.

Janet: I think we've, with this disease it's interesting to see how we have grown and matured because of the disease. Because, you know, where we used to be able to be reactive immediately, like, "Oh mom, why are you doing that?" Like, you know, and not an aggressive, abrupt way, but in a frustration way, to more having empathy and understanding that mom is still there, but the disease has taken her away slowly, and she doesn't have the ability to control these emotions or her actions. And that took a long time for us to recognize.

Janet realized that Erika could not always control her emotions or actions because of her dementia. When she realized this, Janet was able to deal with her emotions and understand Erika. Janet learned to have more patience and empathy when addressing Erika’s forgetfulness or her requests for assistance. Because she learned and grew with her new knowledge, Janet transformed into a more understanding, patient, and empathetic care partner that was able to address Erika’s needs in a thoughtful way.

Growing because of dementia looked similar between Erika’s family and Caroline’s family because both families learned how to overcome their frustration with the person living with dementia and became more accepting of these changes. Similar to Janet, Charles was frustrated with Caroline’s forgetfulness at first. Eventually, he learned that her forgetfulness was due to dementia, and he accepted that he could not do anything about her actions.

Charles: Well, I do realize there's a lot of things that upset me that I couldn't do anything about. You know, so it's not that you go with the flow, it's that you learn to accept things you couldn't accept before. I've learned that especially, I would say, in the last 3 or 4 years. Since her initial diagnosis, I didn't understand it. I had to get it explained to me and I had to have what to expect explained to me as well.

Charles had to learn about dementia, how to care for someone living with dementia, and what to expect in the future. He did not know much about dementia before Caroline's diagnosis which forced him to discover what a dementia diagnosis meant. Charles transformed his unfamiliarity with dementia into knowledge in order to care for Caroline. He learned so he could support his wife through the family's dementia journey. His transformation and growth helped him become more accepting.

The skill of learning and adapting seen in these families was adopted out of necessity. They faced a challenge, so they learned, adapted, grew, and addressed that challenge. Both Janet and Charles worked to overcome difficult situations with their loved ones, but also worked to move past their own expectations for their loved ones to accept who they have become with dementia. This demonstrated perseverance and illustrated the family transformation of adapting in order to address changing needs.

6.5.2 Changing relationships

"Put it in the past and move forward": Spousal relationships

Spousal relationships were heavily emphasized in this study because many of the primary care partners were spouses of people living with dementia. Seija and Daryl, Caroline and Charles, and Evelyn and James were all married couples. Erika was a widow, and she was a care partner for her late husband, Danny, before he passed. Regarding the family transformation, one family in particular stood out in their transformed spousal relationship.

Caroline and Charles were married for 58 years. After the dementia diagnosis, there was an evident shift in their relationship that their daughter Aurora acknowledged. Aurora discussed her parents' disagreements during her childhood and the arguments they had after Charles' retirement. Amazingly, those disagreements rarely occurred after Caroline's diagnosis.

Aurora: After his retirement with her… maybe it's because they just, you know, kind of grew apart there wasn't a whole lot of quiet moments. There was a lot of arguing and stuff like that, but now it's almost as if… it's almost as if they're back in their newlywed stage. […] I mean, you know, the smooching and the cuddling and oh Jesus… yeah… Like I've told them several times, "go get a room." Like it's weird because she actually does not remember any of the animosity that there was between the two of them. And I think he has, instead of dwelling on it, just put it in the past and move forward, right?

Aurora's observation of her parent's relationship changing from arguments and fighting to cuddling and kissing paints a picture of the transformed spousal relationship. Caroline did not remember the animosity between her and Charles, and Charles chose to move past that as well. Charles chose not to dwell on past versions of Caroline who he did not get along with and moved forward to nurture a loving spousal relationship together.

Charles described the relationship with Caroline while she lives in a long-term care home by discussing their romantic gestures.

Charles: Oh, yeah. And I mean, you know, I go there, and I see her there in the hallway and I, you know I look at her and I said, where's my kiss today? You know, and she doesn't care. And she - I said, standing right in the hall. And I said, well, where's my kiss? You know, and so we - she gives me a kiss and good, you know, and then [Caroline]- one of the girls will come by and she'll say, hey, cut it out, you two. Yeah. And that's what [Caroline] does [*laughter*].

Charles worked to maintain the spousal relationship with Caroline in a long-term care home by showing affection and ensuring that he called Caroline his wife in front of others. This relationship was unlike what Aurora viewed in her childhood, where Caroline and Charles often argued. Caroline and Charles' transformed relationship illustrated how Charles focused on what truly mattered to him: Caroline. His acceptance and forgiveness of past challenges and arguments to focus on Caroline's care showed his transformed values of what was important to him. The literature has not explored spousal relationships that have transformed as drastically as Caroline and Charles. The ability of this couple to move forward despite past challenges demonstrated their perseverance and willingness to put their relationship first.

"The next stage will probably be more of a friendship": Parent-child relationships

In this study, many of the participants were the adult children of people living with dementia. Janet and Judith were Erika's daughters, Charlie was Daryl and Seija's son, Aurora was Caroline and Charles' daughter, and Michelle was Evelyn and James' daughter. There were four daughters interviewed and only one son interviewed in this study. This study highlighted an abundance of parent-child relationships and their participation in care. All of the daughters interviewed in this study participated in care by booking appointments, organizing, feeding, and maintaining their parents' dignity and autonomy throughout care. The son, Charlie, interviewed in this study participated in care at a different capacity than daughters, but still contributed to maintaining his father's dignity and autonomy. In this subtheme, the adult children highlighted the transformation that the family experienced regarding the parent-child relationship. Relationships between the adult child and the parent living with dementia or the care partner parent were explored.

Janet and Judith described the transformation they experienced with Erika. Judith first described the difficult transition of caring for a parent compared to previous experiences of being cared for as a child.

Judith: Just it was a hard transition to go from, you know, your mom taking care of you all your life and suddenly you are the one that has to be the parent, you know, and not being able to rely on her to take care of you anymore.

She further described Erika's actions of adjusting Judith's jacket or brushing dirt off of Judith's pants as motherly actions that Erika did before her dementia diagnosis; however, the "bigger taking care of part" was done by Judith. Judith said that the mother-daughter relationship was still present, just at a different level than before. Judith's role as a daughter transformed into a role similar to that of a parent, and she could no longer rely on her mother to fulfill the parental role that she had all of her life, which was difficult for her to experience. Despite this, Erika transformed to fulfill the parental role in a way that she was capable of. Her motherly actions of adjusting Judith's jacket were Erika's way of showing that she cared for Judith. Erika may not have been able to fulfill the parental role like she previously did, but she transformed to maintain her parental role in Judith's life to the best of her ability.

Additionally, Janet discussed her changing relationship with her mother. As Erika's dementia progressed, Janet found that the relationship was similar to that of a mother-daughter relationship, with Janet fulfilling the motherly role. Janet considered what might be the next stage in Erika's dementia progression.

Janet: I'm really happy that she's happy in her surroundings. I'm sad because I see that she's distancing herself from me, if that's the correct terminology. In my mind then I'm going to have to, you know, the next stage will probably be more of a friend [Erika] than a daughter [Erika]. I could see the stages moving.

The transformation from "daughter" to "friend" demonstrated the change in roles that Janet experienced with her mother. This change in relationships illustrated the family transformation because friends are not always considered family members, which shows the detachment Janet feels between her and her mother. Similarly, Aurora briefly discussed that her relationship with Caroline changed from daughter to friend because Caroline did not remember the type of relationship between them, like mother-daughter, only that she knew Aurora when she saw her. The transformed relationship that both Janet and Aurora experienced illustrated how dementia changed the roles and relationships that family members had with people living with dementia.

The parent-child relationship changed between Daryl and Charlie as well. Charlie described his family's experience of watching Daryl when Seija had to leave the house.

Charlie: [The dementia journey] just gradually went from that to if my mom went somewhere we would essentially have to babysit them. You know um… And it… sort of became like… Yeah, my father was a child that needed that level of

> support, you know? You come over here under the guise of watching the game, but he wasn't watching the game. We were just making sure he was safe.

Charlie discussed his transformed role due to the progression of Daryl's dementia. His role as son became the role of "babysitter" in order to make sure that his father was safe when Seija was out. This transformed the parent-child relationship because Charlie was supporting his father in ways Daryl had never required before. Charlie's comparison to Daryl as "a child" acknowledged that Daryl required more care and attention than he had before.

Parent-child relationships go beyond the person living with dementia and their adult child. In Evelyn's family, Michelle described her relationship with her father, James. Michelle said that her and James did not always have a close relationship in her childhood and much of her adult life. Michelle described her initial relationship with James to the relationship she has with him now:

> My dad and I were never close. Like I said, he was actually quite mean. You know like most of our childhood, he was a bit much. And even in part of my mom's diagnosis we- my dad and I went for about a year where we wouldn't speak to each other because he was so angry at me. And I think it was because he thought I should be doing more, but I couldn't. Like I was working full time, I was taking a course that took me two years, I live alone, so I'm you know taking care of my own home. And he didn't understand. So he was really, really quite mean that we didn't speak. […] But I was still allowed to take my mom out, but he and I didn't speak. So it got really bad. But then all of a sudden one day he just… he just started saying please and thank you. Showing gratitude for what I was doing. And he didn't have to apologize because I knew that he understood. And he…

> I think he recognized that I was doing my best. Now I can- I love spending time with my dad. So that's the biggest change. The gift my mom has given us was our dad.

The transformed relationship between this parent and child transformed for the better. Although this change was sudden, Michelle described her current relationship with James as a gift. The tension that was between James and Michelle transformed into one of understanding and gratitude as a result of their experience during the dementia journey. The transformed parent-child relationship illustrated that although dementia was a disruptor, in this case, it resulted in a positive transformation. Michelle continued to talk about their relationship and their transformed roles.

Michelle: So, I think my role with my dad has changed more to the person he leans on and bounces things off of. And our dad has become to us, and to me in particular, I guess, definitely more of the parent I depend on, talk to, lean on, laugh with. So, he's become more of that to me. His role changed to be more of like the parent I lean on and love and laugh with that way.

Michelle's description of her family showed how dementia transformed the relationships between people living with dementia and their family members, and amongst family members as well. Michelle's previous description of her relationship with her father as challenging to her recent description of her father as someone she depended on and laughed with illustrated the drastically transformed relationship between them.

Parent-child relationships illustrated the transformed relationships between parents and their adult children. The changed roles and relationships between the parent living with dementia and their adult child or the parent in care and their adult child were explored. Roles and relationships did not always transform in positive ways, but it was important to acknowledge the changes and experiences of the families in their transformations.

"It's a different relationship than we had in the past": Sibling relationships[3]

In this study, every family had two adult children. There were three sets of daughters and one set of sons in this study, providing some variation in sibling dynamics. Additionally, some siblings lived in a different province than their families, which made it difficult to participate in care. This subtheme explored the relationships, shared roles and responsibilities, and feelings that siblings had for one another in their care journey.

Sibling relationships were complicated and at times strained because of the requirements of care and support for the person living with dementia and the differing involvement of siblings. Some of this differing involvement was related to life circumstances, some to distance, and some to perception. For some siblings, stress and tension caused by differing perceptions of care responsibilities changed over the dementia journey. At one time, there may have been stress and tension, but relationships also grew closer throughout the caring journey as siblings recognized that others were doing the best that they could.

Judith acknowledged the changing relationship between her and her sister and highlighted the positives of their adult relationship. She discussed the importance of understanding each other and getting along, and how that brought them closer together in their adult lives.

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[3] Details of participants' stories and quotes have been redacted to protect participants' privacy and anonymity.

Tension also existed because some siblings lived out of town and were unable to participate in care responsibilities and support. Even though Michelle described some challenges early after their mother was diagnosed, she later described how the sibling relationship transformed with time:

> So, I think now my sister and I have a more… We're even talking more. And again, it was, you know, she was busy with her life. I was busy with mine, but this [dementia] kind of brought us together. So, we're a little bit closer.

Michelle credited dementia as the reason that she and Nora were closer than they were before. Evelyn's diagnosis and care requirements were what brought them closer together. When discussing the recent relationship Michelle had with Nora and James, Michelle said, "It's what I've always wanted." In Evelyn's family, dementia brought the family closer together and transformed the relationships for the better.

The sibling relationships illustrated the family transformation because of the feelings of understanding and compassion, tension and resentment, and shared experience. The sibling relationships were transformed because of dementia, whether they transformed towards a more positive relationship or a negative, tense relationship. Many of these siblings looked to each other for support and relied on each other while providing care for a parent living with dementia. The sibling relationship transformed the family in how they cared for their parent and how they treated one another on their family's dementia journey and illustrated the complexity of relationships.

6.5.3 "He has lightened up": Transformed perspectives

The subtheme *transformed perspectives* highlights how dementia transformed the way people lived their lives and the newfound, life-altering perspectives they had because of dementia. Two separate families described the paternal figure of the family as a changed man because of their experiences caring for their wives with dementia.

Aurora described her father, Charles, as a completely different person from the father she grew up with. Aurora described Charles as someone who was very firm on his stances and was not afraid to argue, but with Caroline's diagnosis, he became more understanding and patient.

Aurora: My father's role… He's lightened up. He has lightened up. I know prior to her being placed in long-term care and living with him, he was getting so frustrated because the way her dementia was… And her saying, "I don't remember, I don't know. I can't, you know, I forget." It appeared to him- and he didn't know if she was doing it on purpose or actually forgetting. And it would drive him up the wall. And, you know, there would be a little bit of conflict but now… you don't see that from him at all. He's understanding. Totally different person.

Aurora talked about Charles' transformation from frustration to understanding with Caroline's dementia. Aurora's descriptions of Charles as someone who "lightened up" illustrated his transformation because of Caroline's dementia. In relation to the subtheme *growing because of dementia,* Charles adapted to Caroline's actions and needs to become a more understanding care partner. He transformed his attitude from frustration to patience and that resulted in a transformed perspective.

Similar to what Aurora said in her interview, Charles discussed that he did not have much knowledge about how to deal with someone living with dementia. Charles learned and became more experienced in dealing with dementia but also focused on what truly mattered to him: Caroline. In his interview, Charles said, “You know some of the - some of the, I don't know what's the word, transgressions or some of the things that had occurred when I was 40 or 50 years old that would really, really get me upset, they don't mean anything anymore. You know, all of that has gone by.” Charles’ perspective of things that mattered to him and things that no longer mattered to him changed with age. This transformation was representative of Charles’ individual transformation. His experience with Caroline’s diagnosis made him realize what was important to him and things he could let go of instead of dwelling on.

In Evelyn’s family, Michelle described her father James’ transformation in personality. She described their relationship as challenging previously, but he transformed into a kind, understanding father figure.

Michelle: And my dad's… my dad's way of being changed like 180 degrees. He went from, you know, being from being- sounds awful, but kind of a bully to being wonderfully kind and understanding. And so that changed. […] He's still very much our father figure and very much… he like- he wants to understand what's going on with us [Michelle and Nora]. He wants to hear us. He's become more of a more of a friend to us almost in that we share more with him now. He's our biggest cheerleader too. Yeah, he's in our corner every time we turn around. And again, I know that he would- no matter what we asked, he'd be there for us.

Michelle’s description of the past version of James to the recent version of James illustrated an individual transformation. James transformed into a friend to Michelle and Nora.

This role may have been similar to the role that Evelyn played for their daughters. Michelle described Evelyn as the parent she could lean on, call, sit down and have tea with, and laugh with. When asked about her relationship with her father now, Michelle said that James has become the parent she depends on, leans on, and laughs with. This illustrated the transformed roles and relationships that parents have with their adult children when a parent goes into a long-term care home. James transformed at the individual level and at the group level to shift the family relationship to a positive, loving, and supportive relationship with his daughters.

The theme *dementia as a transformer* illustrated the changing relationships between family members. Some of these changes were positive, such as closer relationships, and some were negative, such as feelings tension in relationships. Dementia transformed the families in many ways, including the roles people had within the family and the relationships they had with one another. Transformations at the intrapersonal and interpersonal level were explored within and between families, with similarities and differences emerging. Overall, dementia disrupted the lives of the families featured in this study, and transformations occurred as a result.

6.6 Summary

The findings of this study highlighted the roles, relationships, and identities of people living with dementia and their family members, as well as the interconnectedness of these sensitizing concepts as explored through the themes. The first theme, *the meaning of family,* described what people living with dementia and their families felt connected by and defined what family meant to them. In this study, connection meant physical or emotional connections, connections through body language, and connections over distance. Families also discussed that family meant “everything” to them, illustrating their care for one another and the safety and support they felt as part of the family. The feelings of belonging and connectedness that families experienced contributed to their meanings of family.

The second theme *maintaining identity* explored the role of family members in maintaining the identities of people living with dementia. Family members maintained the person living with dementia's identity through roles, music, and fashion. Roles that were established prior to dementia were maintained through tasks and activities. Music played a large part in many participants' lives before their diagnosis and remained with dementia as seen in interactions people living with dementia had with music after their diagnosis. Fashion played a part in maintaining identity by ensuring that people living with dementia looked and felt good in the clothes provided to them by family members. Actions by family members such as asking for opinions, booking nail appointments, and shopping for clothes their loved ones would enjoy ensured that the person living with dementia continued to have their identity supported. The knowledge that family members had for their person living with dementia was seen in their efforts in maintaining identity and dignity.

The third theme *dementia as a disruptor* explored how dementia disrupted the lives of families. The transition into a long-term care home was challenging for many people living with dementia and their families because of the change in environment. Stories of anger, frustration, and acceptance were explored, in addition to the family's disrupted relationships due to the challenges they had to navigate in their transition. The imagined life that people expected for themselves in comparison to the lived reality that they experienced with dementia in the picture illustrated dementia as a disruptor of lives. Adult children quickly realized that dementia was becoming part of their lives with their parent's diagnosis which made them change their ways of living and life outlooks. Dementia also disrupted people living with dementia's preferences which made family members feel unfamiliar with the person they once knew so well. Family members experienced grief over their family members living with dementia. Despite the grief they felt, family members continued to support their loved ones living with dementia and found support for themselves to help them through their grief. *Dementia as a disruptor* illustrated how the lives of people living with dementia and their families changed because of a dementia diagnosis.

The final theme *dementia as a transformer* explored the way dementia transformed the family. Families were forced to grow because dementia transformed their lives, including learning and adapting to a family member's dementia diagnosis. *Dementia as a transformer* discussed many relationships between family members, including spousal relationships, parent-child relationships, and sibling relationships. Spousal relationships explored what was important to couples and their transformed relationships as a result. Parent-child relationships changed between adult children and their parent living with dementia or care partner parent. Sibling relationships transformed with dementia and involved tension between siblings in a few cases. Despite this, siblings also described their relationship as closer because of dementia and their shared experiences. This theme also highlighted how dementia transformed the way people lived because of their newfound, life-altering perspectives. These individual transformations illustrated the shifted perspectives that were a result of dementia transforming their lives.

The four themes *the meaning of family, maintaining identity, dementia as a disruptor,* and *dementia as a transformer* explored the lived experiences of people living with dementia and their families through their dementia journeys. Their stories added to the literature by sharing their unique experiences, family dynamics, and changing roles, relationships, and identities.

Chapter 7: Discussion

The discussion focuses on key findings, including methodological considerations such as the use of voice-centred relational method, individual and group analysis, individual and group identities, complexity and changing relationships, and transformation in dementia. I then discuss study limitations and practical implications. The findings demonstrated the disruptions and transformations for people living with dementia and their families. This study contributes stories about the meaning of family to the literature. The methods of data collection and analysis provided an in-depth look into the family experiences of participants. Because I focused both on individual experiences and the family experience, I also discuss the contributions of thinking about dementia at the group level rather than just focusing on individual experiences. I highlight how individual and group identities of families were explored in this study and their contributions to the literature. I discuss the complex and changing relationships with dementia. Finally, this study contributes to challenging the dominant narrative of decline and struggle of dementia by also focusing on the positive transformations that can happen as a result of dementia.

7.1 Sharing family experiences: The use of photographs, VCRA, and narratives

Viewing family photographs with family members in focus groups was an engaging way to interact with and understand the family relationships and the meaning of family within a group setting. Photographs were used as a prompt to elicit feelings, memories, and engagement. This method permitted a focus on the group level of family relationships by having family members interact, discuss the individuals in the photographs, and share stories about who participants considered family. This data collection method promoted engagement among people living with dementia, provided observations of family relationships, and drew a picture of who was considered family.

Previous research has used narrative approaches to analyze participants' stories in-depth (Daniels et al., 2007). However, a substantial amount of research has used traditional thematic analysis to analyze these stories. In my study, using a voice-centred relational approach (VCRA) was critical to understanding the depth and complexity of participants’ stories. VCRA captured the complexity of stories through the Listening Guide, which helped explore the voices within the narrative, including the self in relation to others, to explore the relationships between voices and within different contexts. This method emphasized listening closely to individual and group voices and highlighted the relationships between family members.

I decided to present the narratives and the thematic analysis of the families in separate chapters to provide context first and then provide an in-depth analysis of voices and perspectives. Narratives provided context for analyzing roles and relationships by exploring the past and present relationships that families had with one another. This painted a broad picture of the family and provided insight into the family dynamics prior to the thematic analysis of the transcripts. Thematic analysis of the families added to the narratives by finding patterns and categorizing excerpts from the transcripts. This helped organize the data, categorize excerpts into themes, and compare perspectives between the four families. This combination of methods added depth to the study by providing layered insights into what family meant to participants, roles, relationships, identities, and perceptions of the self. This study adds to the literature with this unique method of analysis and presentation of the findings to share the stories of people living with dementia and their families, in addition to the thematic analysis of roles, relationships, and identities.

7.2 Individual and group levels of analysis

A unique method of analysis used in this study was the analysis of the family at the individual and group levels. To date, very little research has explored families from a group perspective, but has focused on individual experiences within a family. Analyzing the individual and group data helped explore how participants described their families, who was considered family, and personal and group identities as part of a family unit. This allowed me to explore the complexity of familial relationships and the intrapersonal and interpersonal perspectives on the meaning of family. This study is one of the few studies that analyzes dementia's impact at the individual and group levels of the family, revealing details that dyadic approaches often overlook.

There has been limited work in dementia research about multi-dimensional and dynamic relationships between people living with dementia and their families (Hellstrom et al., 2005). The label "extended family" has been used to address adult children, siblings, grandchildren, and others, many of whom would be considered family members (Roberto & Savla, 2022). Previous literature has explored "family" in dyads, including the person living with dementia and their spouse, adult child, or other relatives, which has overlooked the family as a unit (Roberto & Savla, 2022). This study looked at family as a unit instead of the narrow perspectives of dyadic relationships that dementia research has explored in the past. Approaching the family as a unit instead of individual members added a unique and expansive perspective of the disruptive and transformative impact of dementia on the entire family.

This study contrasts previous literature's definition of family as "two or more people united by marriage, blood, adoptions, or consensual union in a single household" (Sharma, 2013). If this definition were used in this study, people living with dementia in a long-term care home would not be considered family because they did not live in the household. Additional definitions did not include families where people were unmarried, living in multiple households, living with non-family members, and other unique situations (Roberto & Savla, 2022). In this study, participants focused on the relationships that they had with one another more than their blood relations. Participants considered people who were close friends, people who lived in a different province, and people with whom they were not married and lived with their family members. This study illustrated the flexibility of the definition of family and the distinctiveness of individual and group definitions.

7.3 Individual and group identities

In this study, families created an environment where people felt like they belonged. The concept of family belonging included feelings of acceptance, security, shared identity, and mutual respect. Family members described their love, support, and connection with their family. Family members felt a sense of duty toward each other, prioritized family, and supported one another through life. They emphasized teamwork, belonging, and being able to turn to each other in times of need. This finding was similar to research by Cronfalk and colleagues, who discussed the sense of belonging and connection dyads, including a family member and a person living with dementia, experienced after a transition into a long-term care home (2018).

This study showed that individual identities were changed because of dementia in the *dementia as a disruptor* and *dementia as a transformer* sections. Previous identities shifted because of changes in roles and relationships within the family unit. Some family members felt the absence of the person living with dementia after a transition into a long-term care home and had to change their roles to fit the needs of the family, like Charlie's transition into a paternal role with Daryl's absence in their family home. This was a similar finding to previous literature, as family members experienced a transition into a new role after their loved one moved into a long-term care home (Ashbourne et al., 2021). Family members also took on more roles as the person living with dementia changed and eventually transitioned into a long-term care home (Konietzny et al., 2018).

Eifert and colleagues referred to shared identity in a couple as dyadic identity (2015). A dyadic identity is an identity based on being part of a relationship or being part of a couple (Eifert et al., 2015). They claimed that changes in interactions can cause the dyadic identity to be diminished or lost, and the identity cannot continue without the other person participating in the relationship (Eifert et al., 2015). The absence of a partner in the spousal home after a transition into a long-term care home caused a diminished or lost dyadic identity (Eifert et al., 2015). This study argued that not all dyadic identities were diminished or lost with dementia, but were transformed because of dementia. The transformation experienced by couples was not an example of a lost identity, but an example of a transformed identity. The use of the words “diminished” or “lost” feeds into the tragedy discourse about dementia and the stigma that dementia is about loss.

Personhood is defined by Kitwood (1997) as a standing or status bestowed on people with dementia by those around them. Other research has explored how family members maintained a person living with dementia’s identity (Braithwaite Stuart et al., 2022). One of the themes that emerged from my study also discussed the maintenance of a person living with dementia’s identity by family members, specifically through roles, music, and fashion. Although family members played an active role in maintaining the identity of the person with dementia, the person with dementia also continued to assert their identity. For example, Erika continued to notice and comment on people’s clothing. Daryl still responded to conversations about the Maple

Leafs. These examples show that the identity is initially shaped by the person living with dementia and later supported by family members. Family members helped uphold these identities and responded to their ongoing expression.

Maintaining identities through roles, music, and fashion was explored in this study. Families in this study maintained people living with dementia's previous roles and identities by providing an environment that allowed people with dementia to participate in previous activities and routines. This is consistent with findings in the literature where previous research described the maintenance of previous activities or routines, like housework, and its role in personal identity (Chung et al., 2017; Cronfalk et al., 2018). In this study, people living with dementia and family members used clothing to maintain identity, including choosing clothes that the person living with dementia would have chosen for themselves or wearing clothes that held meaning from their favourite team. Research on clothing and embodied identity was previously explored with people living with dementia (Buse & Twigg, 2015; Twigg & Buse, 2013). Clothing was not only what people wore, but it was also a biographical object that contributed to a person's identity (Buse & Twigg, 2015; Twigg & Buse, 2013). Twigg and Buse described clothing as a talking point for life narratives, especially within care settings, by evoking memories from previous activities, relationships, and events (2013). This was represented in this study through the interactions with family members and the stories that comments on clothing invoked.

Contrary to previous literature, this study illustrated that people living with dementia continued to connect with the self. Previous literature discussed that family relationships helped reinforce people living with dementia's sense of self and feelings of selfhood and personhood (Hellstrom et al., 2005; Hellstrom et al., 2007). In this study, while family members did reinforce selfhood and personhood by maintaining identity, identities were established by the person living with dementia prior to the dementia diagnosis. Family members maintained established identities during the dementia journey. Family members also reinforced people living with dementia's sense of self by maintaining previous activities and continuing to provide opportunities for engagement and connection. Partnerships between people living with dementia and their family members helped maintain previous identities and illustrated the connection and understanding they have with one another. Previous habits, activities, and interests were deeply rooted in a person's identity and maintaining previous activities preserved identities and the self (Cronfalk et al., 2018). The findings of this study have exposed the limits of Kitwood's theories on the concept of personhood, specifically the fixed approaches to selfhood and personhood that do not acknowledge dynamic and transformative experiences of people living with dementia and their families. People living with dementia have a sense of self regardless of social and relational aspects, although relationships can help reinforce a sense of self, selfhood, and personhood.

The concepts of the self and personhood are dependent on the relationships between individuals and others in society (Kitwood, 1997). The idea that self and personhood are dependent on the relationships people have with others and are given to people by their social circles is limiting people's autonomy. Kitwood's focus on personhood as a "status" that is bestowed by others does not address the dynamic nature of the self and personhood. This concept does not acknowledge the changes that people living with dementia experience and the changes that the people within their social circles experience as well. A fixed approach to the self and personhood that does not acknowledge the dynamic and transformational experiences of people living with dementia and families does not accurately describe the participants within this study. This study challenges Kitwood's view of personhood as externally bestowed and shows that identity can be co-constructed and maintained by the person living with dementia.

7.4 Complex and changing relationships

This study explored the relationships among spouses, parents and adult children, siblings, and grandchildren. The findings illustrated the complexity of relationships within and between families in the family narratives and analysis. In a study by Eskola and colleagues, they explored how couples maintained intimacy with dementia in the picture, including holding hands or hugging as simple ways to maintain connection (2022). In this study, spousal relationships were maintained similarly through physical interactions. However, couples also used language to show feelings of connection, like saying “my wife” or “my husband” when addressing one another, which has not been explored in depth in the literature.

In this study, parent-child relationships that were strained before the diagnosis and transformed into a positive relationship after the diagnosis contrasted with previous literature, where close relationships before a dementia diagnosis resulted in continued positive relationships in care (Kokorelias et al., 2022; Venters & Jones, 2020). Previous literature explored feelings of frustration and resentment in siblings when they felt that one sibling was not doing enough to care for their parent living with dementia (McDonnell et al., 2013). Similarly, in this study, multiple siblings experienced feelings of resentment toward their sibling regarding care.

Previous research on intergenerational relationships showed that having positive relationships with family members promoted healthier behaviours, positive mental health outcomes, and increased feelings of social support, social connection, emotional support, and self-esteem (Perion et al., 2021; Thomas et al., 2017). Similarly, although this study featured one grandchild, observations in this study illustrated that interactions between the person living with dementia and the grandchild contributed to the well-being of both individuals through the reciprocal relationship they shared. Interactions that included smiles, shared laughter, and were gentle, kind, and patient promoted connections between generations.

7.5 Transformation and Dementia

The theme *dementia as a transformer* adds unique findings to the current literature. Transformation means a marked change, including changes in the participant, the family, roles, relationships, or identities. Many studies in dementia research focused on dyads instead of family units, which separated the experiences of the family as a whole into groups of two people. Because of the focus on dyads, the exploration of the transformations within the family unit has been seldom explored in dementia literature. This study highlighted the transformative impact of dementia on multiple families. Transformations occurred at the individual and group levels, which demonstrated how dementia impacted the family as a whole, not just dyads in care. The findings highlighted transformations to roles, relationships, and identities that occurred at the individual and group level.

Instead of focusing on the burden, loss, and stress that families often feel after a dementia diagnosis and a move into a long-term care home, I focused on the relationships that families had with one another. This study emphasized that transformations because of dementia can be positive, which contrasts with the tragedy narrative that much of dementia research focuses on. This unique finding adds to the literature by sharing the lived experiences of people living with dementia and their families contributed to the literature by sharing positive and negative perspectives, challenges, and transformations that families experienced. These experiences are valuable in sharing the family experiences within their own unique contexts.

The transformation families experienced in this study were both positive and negative transformations. Previous research on dementia often focused on the negative, tragic narratives of people living with dementia and their families (Bailey et al., 2021). This perpetuates stigma about dementia by primarily focusing on the loss, grief, stress, and challenges that families face. This study focused on telling authentic family narratives by including the positive and negative experiences of families. The stories shared by family members illustrated the complexity of experiences when supporting a family member with dementia. By sharing these experiences, this study challenges the idea that dementia is a negative disease centred around loss. Transforming, learning, adapting, growing, and persevering through a dementia diagnosis were experienced by families in this study. This showed that dementia is not solely about loss and grief, but that the dementia journey is complex and multifaceted, filled with significant challenges and transformations.

Dementia can be about transformation, overcoming challenges, and growing together as a family. While this study does not suggest that dementia is always a positive experience, it shows that growth, connection, and transformation are possible outcomes of the dementia journey. In this way, I was able to capture the complexity of the experiences of dementia for families.

7.6 Limitations and positionality

While there were many strengths of this study, particularly in the depth of data and the relationships between the researcher and participants, there were also limitations. This study was clearly outlined as a study about the family. Families that participated were aware of this and may have only shared their perspectives on who is considered in family by society (i.e. blood relatives) instead of who *they* considered to be family. This preconceived idea of what family is by society may have influenced participants’ answers.

Participants were recruited from a local advocacy group and community program. These groups were very family-oriented. Generally speaking, these families care for one another, have regular communication with each other, and bring the person living with dementia to the program to engage with others. These families prioritized spending time and caring for their family members. The likelihood of families being close and having good relationships with each other was high because of these groups. This could be a potential limitation because it limits the findings of this study to the experiences of families with close relationships and does not highlight the experiences of families with complex or distant relationships.

Additionally, interviews were very limited with the people living with dementia. Focus groups were conducted, including the person living with dementia and their family members, with three out of the four families. In these focus groups, although the person living with dementia reacted in their body language to the photographs examined, there were few verbal reactions to them. This was somewhat limiting in the analysis because there were very few quotations from the people living with dementia that were able to be analyzed.

The diversity of participants in this study was limited. All of the participants in this study were Caucasian. More women than men living with dementia were featured in this study. There were more daughters than sons in this study. There were no daughter-son combinations among the participants in this study. All married individuals in the study were heterosexual couples. This may limit the findings as it does not explore diverse perspectives, including perspectives from ethnic or racialized minority groups, LGBTQ+ individuals, mixed gender siblings, and gendered perspectives of living with dementia.

My position as a student and someone who has working relationships with the participants in this study must be acknowledged as a potential limitation. To address this, my committee and I ensured that none of the participants felt pressured to participate because of my ongoing relationship with them and informed them that their participation was voluntary. Additionally, I am very close with my family and agree with the participants that "family means everything," so there is potential bias in my analysis of what family looks like and means to me. I made sure to carefully consider my opinions of family in my analysis of the data through reflecting and journaling. A topic that was brought up multiple times in my journal and in conversations with others was about what family meant to me and how my assumptions about family could influence my analysis of the data. I was very conscious of my assumptions and ensured that my definition did not interfere with the definitions families developed and shared with me. I attempted to ensure that the findings presented in this thesis reflect the data, not a reflection of my perceptions of family. Member checking with the family members who participated in the study helped to ensure the trustworthiness of my representations of their experiences.

7.7 Practical implications

This study emphasized that practitioners need to view the family as a whole, rather than focusing on primary informal care partners. Dividing people living with dementia and their care partners into dyads overlooks the family unit as a whole, including the transformative experiences of all family members. Practitioners should consider whole-family support models in order to recognize and support the emotional well-being of all family members.

This study explored stories of positive transformation and resilience, showing that dementia is not always a negative experience. The findings that highlight the positive transformations of families with dementia have the power to shift public perceptions of what it is like to live with dementia and what a dementia diagnosis means for families. This finding can help shift the perspective from the fear and loss associated with dementia to resilience and connections between families.

This study highlighted how families respectfully support the identities of people living with dementia. Utilizing how supportive environments helped maintain identities can be used by families and practitioners to help support more people living with dementia. To facilitate this, practitioners can provide activities and roles that maintain identity and expression of the self, and access to the long-term care home is important for this to occur.

Families supporting a person living with dementia in a long-term care home should know their rights as a family and the rights of the person living with dementia. Families have a right to access the space to visit their family member living in a long-term care home. This study highlighted how families can help maintain identities by visiting, communicating, and knowing their person.

While conducting this study, I aimed to address the stigma associated with dementia through its use of language and the emphasis on the sense of self and identity that people living with dementia maintain even with the progression of dementia. The use of inclusive and person-centred language in this study emphasized that the person living with dementia is more than just a patient or someone with an illness. This study aimed to avoid the use of biomedical terminology or behavioural terms, like “wandering” or “aggression,” to focus on the social and relational aspects of dementia. Using person-centred language is a simple step that gives people with dementia respect and dignity. Additionally, this study addressed the myth that people living with dementia do not maintain their sense of self with the progression of dementia. This myth perpetuates the harmful stigma that people living with dementia lose their sense of identity with memory impairment; however, this study addresses and dismisses this myth by sharing the experiences of people living with dementia and their families in maintaining identity throughout the dementia journey.

Although this study focused on the family unit, further research on larger units will provide broader perspectives that contribute to the whole picture, not the narrow, repetitive findings explored through dyads in dementia research. Future research on roles, relationships, and identities with larger units, such as the family unit, is still worth exploring. Additionally, research exploring new identities emerging in people living with dementia would be interesting to see and add to the theme of *dementia as a transformer.* Building from this study by exploring the complex relationships in a family with dementia in the picture, instead of focusing on tragedy narratives, would be beneficial to fighting stigma and sharing the lived experiences of people living with dementia and their families.

Chapter 8: Conclusion

This study aimed to explore people living with dementia and family members' meaning of family after a transition into a long-term care home. It aimed to explore the construct of family, including the meaning of family, roles, relationships, and identities. The family narratives were presented to provide context and paint a picture of the early lives and dementia journeys of families. Analysis using VCRA provided insight into the sensitizing concepts of roles, relationships, and identities.

From the findings of this study, themes such as *the meaning of family*, *maintaining identity, dementia as a disruptor,* and *dementia as a transformer* were revealed. Disrupted and transformed roles, relationships, and identities were discussed, which illustrated dementia as a disruptor and a transformer of lives. Complex relationships and unique experiences were shared, which provided insight into the lives of families experiencing a dementia diagnosis.

Although there were limitations to this study, the unique experiences of these families provided insight into the lived experiences of people living with dementia and their families. Future studies should continue to explore family units instead of dyads and emerging identities in people living with dementia.

References

Ashbourne, J., Boscart, V., Meyer, S., Tong, C. E., & Stolee, P. (2021). Health care transitions for persons living with dementia and their caregivers. *BMC Geriatrics, 21*(1). https://doi.org/10.1186/s12877-021-02235-5

Bailey, A., Dening, T., & Harvey, K. (2021). Battles and breakthroughs: representations of dementia in the British press. *Ageing and Society*, *41*(2), 362–376. doi:10.1017/S0144686X19001120

Baird, A., & Thompson, W. F. (2018). The impact of music on the self in dementia. *Journal of Alzheimer's disease: JAD*, *61*(3), 827–841. https://doi.org/10.3233/JAD-170737

Barbour, R. S. (2010). Chapter 17: Focus groups. In *The SAGE Handbook of Qualitative Methods in Health Research* (pp. 326-352). SAGE Publications.

Barken, R. (2017). Reconciling tensions: Needing formal and family/friend care but feeling like a burden. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 36*(1), 81–96. https://doi.org/10.1017/s0714980816000672

Batra, S., Sullivan, J., Williams, B. R., & Geldmacher, D. S. (2016). Qualitative assessment of self-identity in people with advanced dementia. *Dementia*, *15*(5), 1260–1278. https://doi.org/10.1177/1471301215601619

Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P., & Poland, F. (2019). Maintaining social connections in dementia: A qualitative synthesis. *Qualitative Health Research, 30*(1), 23–42. https://doi.org/10.1177/1049732319874782

Braithwaite Stuart, L., Hedd Jones, C. & Windle, G. (2022) A qualitative systematic review of the role of families in supporting communication in people with dementia. *International*

Journal of Language & Communication Disorders, 57, 1130–1153. https://doi.org/10.1111/1460-6984.12738

Bright, F. (2016, November 10). Researching Relational Practice Using the Voice Centered Relational Approach [Paper presentation]. Relational Practices in Health and Healthcare, Healing Through Collaboration, Cleveland, Ohio.

Busted, L. M., Nielsen, D. S., & Birkelund, R. (2019). The importance of bringing the family together. exploring the experience and meaning of family health conversations in Dementia Care. *Open Journal of Nursing, 09*(11), 1153–1172. https://doi.org/10.4236/ojn.2019.911085

Buse, C.E., & Twigg, J. (2015). Clothing, embodied identity, and dementia: Maintaining the self through dress. *Age, Culture, Humanities*. 2. 10.7146/ageculturehumanities.v2i.130611.

Cambridge University Press. (2025). *Role*. In *Cambridge Dictionary*. Retrieved June 9, 2025, from https://dictionary.cambridge.org/dictionary/english/role

Ceci, C., Symonds Brown, H., & Judge, H. (2018). Rethinking the assumptions of intervention research concerned with care at home for people with dementia. *Dementia*, 19(3), 861–877. https://doi.org/10.1177/1471301218790037

Ceci, C., Symonds Brown, H., and Prukis, M. E. (2019). Seeing the collective: family arrangements for care at home for older people with dementia. *Ageing and Society, 39*(6), 1200–1218. doi:10.1017/S0144686X17001477

Chen, C. K., Clayton, K., & Chodosh, J. (2017). The relationship between "what we believe" and "how we care" among daughters caring for a parent with dementia. *American Journal of Alzheimer's Disease & Other Dementias, 32*(2), 90–95. https://doi.org/10.1177/1533317517689875

Chirico, I., Ottoboni, G., Valente, M., & Chattat, R. (2021). Children and young people's experience of parental dementia: A systematic review. *International Journal of Geriatric Psychiatry, 36*(7), 975–992. https://doi.org/10.1002/gps.5542

Chung, P. Y. F., Ellis-Hill, C., & Coleman, P. (2017). Supporting activity engagement by family carers at home: maintenance of agency and personhood in dementia. *International Journal of Qualitative Studies on Health and Well-Being*, *12*(1). https://doi.org/10.1080/17482631.2016.1267316

Cohen-Mansfield, J., Golander, H., & Arnheim, G. (2000). Self-identity in older persons suffering from dementia: Preliminary results. *Social Science and Medicine, 51*, 381-394.

Cresswell, J. W. (2013). Qualitative inquiry & research design: Choosing among five approaches (3rd ed.). *SAGE Publications.*

Cronfalk, B. S., Norberg, A., & Ternestedt, B. M. (2018). They are still the same - family members' stories about their relatives with dementia disorders as residents in a nursing home. *Scandinavian Journal of Caring Sciences*, *32*(1), 168–176. https://doi.org/10.1111/scs.12442

Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer's disease: one couple's story. *Families, Systems & Health, 25*(2), 162+. https://link-gale-com.ezproxy.lakeheadu.ca/apps/doc/A166537348/AONE?u=ocul_lakehead&sid=bookmark-AONE&xid=470b5d96

Duggleby, W., Schroeder, D., & Nekolaichuk, C. Hope and connection: the experience of family caregivers of persons with dementia living in a long-term care facility. *BMC Geriatrics*, *13*, 112 (2013). https://doi.org/10.1186/1471-2318-13-112

Egdell, V. (2013). Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. *Ageing and Society*, *33*(5), 888–907. doi:10.1017/S0144686X12000311

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education*, *46*(6), 357–367. https://doi.org/10.1080/19325037.2015.1099482

Eskola, P., Jolanki, O., & Aaltonen, M. (2022). Through thick and thin: The meaning of dementia for the intimacy of ageing couples. *Healthcare, 10*(12), 2559. https://doi.org/10.3390/healthcare10122559

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia*, *13*(3), 330–349. https://doi.org/10.1177/1471301212473882

Feldman, H. H., & Estabrooks, C. A. (2017). The Canadian dementia challenge: Ensuring optimal care and services for those at risk or with dementia throughout the country. *Canadian Journal of Public Health, 108*(1). https://doi.org/10.17269/cjph.108.5852

Fels, D. I., & Astell, A. J. (2011). Storytelling as a model of conversation for people with dementia and caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, *26*(7), 535–541. https://doi.org/10.1177/1533317511429324

Gilligan, C., Spencer, R., Weinberg, K., & Bertsch, T. (2003). On the Listening Guide: A voice-centred relational model. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.). In *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 157–172). American Psychological Association.

Grigorovich, A., Rittenberg, N., Dick, T., McCann, A., Abbott, A., Kmielauskas, A., Estioko, V., Kulasingham, S., & Cameron, J. I. (2016). Roles and coping strategies of sons caring for a parent with dementia. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, *70*(1), 7001260020p1–7001260020p9. https://doi.org/10.5014/ajot.2016.017715

Grundberg, Å., Sandberg, J., & Craftman, Å. G. (2021). Childrens' and young adults' perspectives of having a parent with dementia diagnosis: A scoping review. *Dementia*, *20*(8), 2933–2956. https://doi.org/10.1177/14713012211023653

Gubrium, J.F. & Holstein, J.A. (2001). Institutional selves: Troubled identities in a postmodern world. Oxford University Press.

Hellström, I., Nolan, M., & Lundh, U. (2005). 'We do things together:' A case study of 'couplehood' in dementia. *Dementia*, *4*(1), 7–22. https://doi.org/10.1177/1471301205049188

Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining `couplehood:' Spouse' strategies for living positively with dementia. *Dementia*, *6*(3), 383–409. https://doi.org/10.1177/1471301207081571

Hellström, I., & Torres, S. (2016). The "not yet" horizon: Understandings of the future amongst couples living with dementia. *Dementia*, *15*(6), 1562–1585. https://doi.org/10.1177/1471301214565673

Herron, R. V., & Rosenberg, M. W. (2017). Dementia in rural settings: Examining the experiences of former partners in care. *Ageing and Society, 39*(2), 340–357. https://doi.org/10.1017/s0144686x17000952

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, *20*(4), 12–17. https://doi.org/10.7748/nr2013.03.20.4.12.e326

Jacklin, K., & Walker, J. (2019). Cultural understandings of dementia in indigenous peoples: A qualitative evidence synthesis. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 39*(2), 220–234. https://doi.org/10.1017/s071498081900028x

Jacobsen, K. (2022, February 18). Why words matter: "Care partner" vs "Caregiver" & more. Alzheimer's San Diego. https://www.alzsd.org/why-words-matter-care-partner-vs-caregiver-more/#:~:text=%E2%80%9CCaregiver%E2%80%9D%3A%20Why%20make%20a,care%20partner%20partners%20in%20care.%E2%80%9D

Josselson, R. (1996). On writing other people's lives: Self-analytic reflections of a narrative researcher. In *Ethics and Process in the Narrative Study of Lives* (pp. 60-71). SAGE Publications.

Kelly, S. E. (2010). Chapter 16: Qualitative interviewing techniques and styles. In *The SAGE Handbook of Qualitative Methods in Health Research* (pp. 307–326). SAGE Publications.

Kinchin, I., Edwards, L., Adrion, E., Chen, Y., Ashour, A., Leroi, I., Brugulat-Serrat, A., Phillips, J., Masterson, F., & Kochovska, S. (2022). Care partner needs of people with neurodegenerative disorders: What are the needs, and how well do the current assessment tools capture these needs? A systematic meta-review. *International Journal of Geriatric Psychiatry, 37*(7). https://doi.org/10.1002/gps.5764

Kitwood, T. (1997). Dementia reconsidered: The person comes first. Open University Press, Buckingham.

Kleinman, S., Stenross, B., McMahon, M. (1994). Privileging Fieldwork Over Interviews: Consequences for Identity and Practice. *Symbolic Interaction, 17*(1), 37-50. JAI Press.

Kłosińska, U., & Leszko, M. (2023). Family relationships as a source of narrative identity of people with advanced dementia. *BMC Geriatrics*, *23*(1). https://doi.org/10.1186/s12877-023-04258-6

Koehn, S. D., Donahue, M., Feldman, F., & Drummond, N. (2019). Fostering Trust and sharing responsibility to increase access to dementia care for immigrant older adults. *Ethnicity & Health, 27*(1), 83–99. https://doi.org/10.1080/13557858.2019.1655529

Kokorelias, K. M., Rittenberg, N., Law, A., Wan, N. T., Machon, J., Arfeen, Y., & Cameron, J. I. (2022). Brothers and sisters sharing in the care of a parent with dementia. *Dementia, 21*(3), 765–780. https://doi.org/10.1177/14713012211053970

Konietzny, C., Kaasalainen, S., Dal-Bello Haas, V., Merla, C., Te, A., Di Sante, E., Kalfleish, L., & Hadjistavropoulos, T. (2018). Muscled by the system: Informal caregivers' experiences of transitioning an older adult into long-term care. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 37*(4), 464–473. https://doi.org/10.1017/s0714980818000429

Kontos, P.C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society, 24*, 829-849.

La Fontaine, J. & Oyebode, J.R. (2014). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society*, *34*(7), 1243–1272. https://doi.org/10.1017/s0144686x13000056

Leary, M.R., & Tangney, J.P. (2003). The self as an organizing construct in the behavioral and social sciences. In M.R. Leary & J.P. Tangney (Eds.), *Handbook of Self and Identity* (pp. 3-14). New York, NY: Guilford Press. Norberg, 2019.

McDonnell E, Ryan AA. (2013). The experience of sons caring for a parent with dementia. *Dementia*. *13*(6):788-802. doi:10.1177/1471301213485374

Merriam-Webster. (2024). *Stigma definition & meaning*. Merriam-Webster. https://www.merriam-webster.com/dictionary/stigma

Mullin, J., Simpson, J., Froggatt, K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia*. *12*(2):177-191. doi:10.1177/1471301211418096

Perion, J., Steiner, V., & Ames, A. (2021). "It makes me feel like good inside because I helped him do stuff" – perceptions of psychological well-being in adolescents providing dementia care. *Journal of Aging Studies*, *56*, 100908. https://doi.org/10.1016/j.jaging.2020.100908

Phinney, A., Macnaughton, E., Wiersma, E., Sutherland, N., Marchese, C., Cochrane, D., & Monteiro, A. (2023). Making space at the table: engaging participation of people with dementia in community development. *International Journal of Geriatric Psychiatry*. 5984. https:// doi.org/10.1002/gps.5985

Purves, B.A. & Phinney, A. (2012). Family voices: A family systems approach to understanding communication in dementia. *Canadian Journal of Speech-Language Pathology and Audiology*. *36*. 284-300.

Riessman, C. K. (2007). *Narrative methods for the human sciences*. SAGE Publications.

Roberto, K. A., & Savla, J. (2022). Extended family caregivers for persons living with dementia. *Journal of Family Nursing*, *28*(4), 396–407. https://doi.org/10.1177/10748407221115455

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's Disease. *Ageing and Society, 12*, 443-461.

Shannon, K., Bail, K., & Neville, S. (2019). Dementia-Friendly community initiatives: An integrative review. *Journal of Clinical Nursing, 28*(11–12), 2035–2045. https://doi.org/10.1111/jocn.14746

Sharma, R. (2013). The Family and Family Structure Classification Redefined for the Current Times. *Journal of Family Medicine and Primary Care. 2*(4):306-10. doi: 10.4103/2249-4863.123774. PMID: 26664832; PMCID: PMC4649868.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R. S., Auret, K. A., Clayton, J. M., Agar, M., & Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics*, *30*(11), 1639–1647. https://doi.org/10.1017/s1041610218000741

Smebye, K. L., & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: A qualitative, hermeneutic study. *BMC Nursing*, *12*(1). https://doi.org/10.1186/1472-6955-12-29

Smith, L., Morton, D., & van Rooyen, D. (2022). Family Dynamics in dementia care: A phenomenological exploration of the experiences of family caregivers of relatives with dementia. *Journal of Psychiatric and Mental Health Nursing*, *29*(6), 861–872. https://doi.org/10.1111/jpm.12822

Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analysis. *Doing Social Psychology Research*, 229–254. https://doi.org/10.1002/9780470776278.ch10

Sun, W., Bartfay, E., Smye, V., Biswas, S., Newton, D., Pepin, M., & Ashtarieh, B. (2022). Living well with dementia: The role volunteer-based social recreational programs in promoting social connectedness of people with dementia and their caregivers. *Aging & Mental Health, 26*:10, 1949-1962, DOI: 10.1080/13607863.2021.1950614

Thomas, P. A., Liu, H., & Umberson, D. (2017). Family relationships and well-being. *Innovation in Aging, 1*(3). https://doi.org/10.1093/geroni/igx025

Twigg, J., & Buse, C.E. (2013). Dress, dementia and the embodiment of identity. Spec. issue of *Dementia, 12*(3), 326-36

van Corven, C. T., Bielderman, A., Lucassen, P. L., Verbeek, H., Lesman-Leegte, I., Depla, M. F., Stoop, A., Graff, M. J., & Gerritsen, D. L. (2022). Family caregivers' perspectives on their interaction and relationship with people living with dementia in a nursing home: A qualitative study. *BMC Geriatrics, 22*(1). https://doi.org/10.1186/s12877-022-02922-x

Venters, S., & Jones, C. J. (2020). The experiences of grandchildren who provide care for a grandparent with dementia: A systematic review. *Dementia*, *20*(6), 2205–2230. https://doi.org/10.1177/1471301220980243

Wiersma, E. C. & Dupuis, S.L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies. 24*(4), 278-291. https://doi.org/10.1016/j.jaging.2010.08.003

Yin, R. K. (2003). *Case study research: Design and methods* (3rd ed.). SAGE Publications.

Zhou, Y., Hasdemir, D., Ishado, E., Borson, S., & Sadak, T. (2023). Validation and expansion of a behavioral framework for Dementia Care Partner Resilience (CP-R). *Dementia, 22*(7), 1392–1419. https://doi.org/10.1177/1471301223118116

Appendix A: Forms of participants

Information letter

Participant consent and signature page

Demographic questionnaire

Information letter

The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis

Dear potential participants,

You have been invited to participate in the study “The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis.” You have been selected because of your personal experiences with the topic. Please read the following information letter carefully. You are welcome to share any questions or concerns with the research team. Your participation in this study is completely voluntary. If you are willing to participate, please sign the consent form and return it to the research team.

Thank you for your time!

Dr. Elaine Wiersma, Dr. Nisha Sutherland, and Maaja Sepa

1. RESEARCH TEAM

Who is conducting the project?

Principal Investigators: **Elaine Wiersma, PhD**

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2. INVITATION AND PROJECT PURPOSE

What is the purpose of the project?

This study will tell the story of families experiencing a dementia diagnosis, particularly once a family member has moved into long-term care. I hope to explore what family means to people with dementia and their family members, as well as changes to roles, relationships, and identities throughout the dementia journey. You and your family are invited to participate in this study because of your personal experiences with this topic.

3. STUDY PROCEDURES

What will you do if you take part in this research?

You will take part in activities where you will be asked to share your experiences and opinions about your experience with a dementia diagnosis in your family. This would include one (or more) of the following:

☐ **Individual Interview**

You would meet with a researcher for a guided conversation about your experiences and opinions. These individual interviews would last 30-60 minutes and would take place in a private office or some other location of your choice. The interviews will be audio recorded and transcribed.

☐ **Focus Group**

You would take part in a group interview with your family members. The researcher would ask questions about your family's experiences and opinions, and you would discuss these together as a group. You are encouraged to bring family photos to the interview as a prompt for discussions with your family. The group interview would last 45-60 minutes and would take place in a private meeting room in a community or university setting. The researcher would take notes describing the process and the conversation would be audio and/or video recorded and transcribed.

What will happen with this information?

The information gathered from these activities will be analysed by the research team. The recordings will be locked at the Centre for Education and Research on Aging and Health (CERAH), and written materials will not include your name. Photos and video recordings containing your image may be viewed by members of the research team but will not be shared with the public in the final research paper. All information will be stored for seven years after the end of the study, and it may be used for additional research on related topics in the future.

4. STUDY RESULTS

How will the results of the study be shared?

The results of this study will be shared widely through written reports and presentations for community groups, researchers, and students. Your information will be anonymous. You are welcome to request a summary of the research results and findings.

5. POTENTIAL RISKS OF THE STUDY

Is there any way this study could be bad for you?

We do not think that participating in this study could harm you or be bad for you. You are welcome to decline to answer questions for any reason without being questioned by the researchers. Please let one of the researchers know if you have any concerns, and you may withdraw from the activity if you wish. Because the research activities may occur in a group setting, there is a potential loss of confidentiality.

6. POTENTIAL BENEFITS OF THE STUDY

Will being in this study help you?

By taking part in this research, you will have the chance to contribute to current research and engage in conversations about the meaning of family.

7. CONFIDENTIALITY

How will your identity be protected?

Because the research activities may occur in a group setting, there is a potential loss of confidentiality because we cannot control what other participants do with the information discussed. Your name will not be associated with the information that comes from this study. All the study materials will refer to you by a code number or a false name.

How will your data be stored?

All data will be kept in a locked filing cabinet in a locked office at the Centre for Education and Research on Aging and Health. Online data will be stored in a password protected Google Drive. Information that discloses your identity will not be released without your consent unless required by law.

8. PAYMENT

Will you be paid for your time taking part in this study?

We will not pay you for the time you take to be in this study.

9. POTENTIAL CONFLICT OF INTEREST

It should be acknowledged that the research team has a well-established relationship with many of the potential participants. The research team has reflected on our positions as volunteers, advocates, and friends of people with dementia and we have concluded that there are no conflicts of interest in this study. Your relationship with the advocacy group and/or the community program will not change because of your decision to participate (or not) in the research project.

10. CONTACT FOR INFORMATION ABOUT THE STUDY

Who can you contact for support?

Given the potentially sensitive nature of the research topic, there is the possibility that you may require additional support. Below are some resources available to you and your family:

- The Alzheimer's Society: www.alzheimer.ca/thunderbay/en/help-support/programs-services
- Ontario Caregiver Helpline: www.ontariocaregiver.ca/help/helpline/#how-to-access-helpline
- Dementia Alliance International: www.dementiaallianceinternational.org/get-support/join-a-support-group

Who can you contact if you have questions about the study?

If you have any questions or concerns about the study, please contact one of the research investigators. The names and telephone numbers are listed at the top of the first page of this form.

Who can you contact to withdraw from this study?

If you would like to withdraw from this study, please contact one of the research investigators. The names and contact details are listed at the top of the first page of this form. You will be able to withdraw from this study until the data has been submitted for the final thesis paper.

11. CONTACT FOR COMPLAINTS

Who can you contact if you have complaints or concerns about the study?

This study has been approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

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Participant consent and signature page

The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis

Taking part in this study is entirely up to you. You are a volunteer, and you can withdraw from the study at any time and may choose not to answer any question. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact.

My signature below signifies that I agree to the following:

- ✓ I have read and understood the information contained in the Information Letter.
- ✓ I agree to participate.
- ✓ I understand the risks and benefits to the study.
- ✓ I understand that I am a volunteer and can withdraw from the study at any time and may choose not to answer any question.
- ✓ I understand that the data will be securely stored at the Centre for Education and Research on Aging and Health (CERAH) for a minimum period of 7 years following completion of the research project.
- I have received a copy of this information sheet for my own records.
- ✓ I will remain anonymous.
- ✓ All of my questions have been answered.

I consent to audio and video recordings during interviews/focus groups. **YES** **NO**

____

Participant Signature Date

____

Printed Name of the Participant

____

Proxy Signature (if applicable) Date

____

Printed Name of the Proxy (if applicable)

I would like to receive a copy of the research results. **YES** **NO**

If yes, please provide your email or mailing address for the research results:

____

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Demographic questionnaire – People with dementia and care partners

The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis

1. How old are you? ____
2. What is your gender identity? ____
3. What is your ethnicity (i.e. Caucasian, Black, Asian, Indigenous, etc.)?

   ____

4. Are you married? Yes No

If yes, how long have you been married? ____

5. Have you or your family member been diagnosed with dementia? Yes No

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Demographic Questionnaire – Family members

The family picture: A collection of family case studies exploring roles, relationships, and identities after a dementia diagnosis

1. How old are you? ______________________________
2. What is your gender identity? ______________________________
3. What is your ethnicity (i.e. Caucasian, Black, Asian, Indigenous, etc.)?

   ____
4. What is your relationship to a person living with dementia (i.e. son/daughter, husband/wife, grandchild, friend, etc.)? ______________________________
5. Has your family member been diagnosed with dementia? Yes No
6. How long have they lived in a LTC home? ______________________________

Appendix B: Interview guides

Interview Guide – People living with dementia

Interview Guide – Family members

Interview Guide – Focus groups

Interview Guide – People living with dementia

Topic	Question	Probe
Introduction	Tell me about yourself.	How old are you? Where do you live? If you could tell someone new three things about yourself, what would you say?
Family	How would you describe your family?	What do you like to do together? How would you describe your relationship?
Family	Who is considered your family to you?	How do you see your role in your family?
Family	What does family mean to you?	
Pictures	Who is in this picture? Are they your family?	

Interview Guide – Family members

Topic	Question	Probe
Introduction	Tell me about yourself.	How old are you? What is your relationship to *person with dementia*?
Family	Who is considered your family to you?	Are they in Thunder Bay with you? Are they living elsewhere?
Family	How would you describe your family?	Do you spend a lot of time together? How would you describe your family relationships? What would you say your role within your family is? How would other people describe your family?
Family	What does family mean to you?	
Caring for a person living with dementia	Tell me about your caring journey with your family member.	
Family identity	How has family identity changed since the dementia diagnosis? **AND/OR** How has it changed since *person with dementia* moved into long-term care?	Earlier you described your family as ___, how would you describe your family now?
Roles	How have your roles changed as a family since the dementia diagnosis? **AND/OR** How have your roles changed as a family since *person with dementia* moved into long-term care?	How would other people describe your role?

Relationships	How have your relationships changed as a family since the dementia diagnosis? **AND/OR** How have your relationships changed as a family since *person with dementia* moved into long-term care?	If so, how?
Identity	Do you feel like your identity has changed since the dementia diagnosis? **AND/OR** Do you feel like your identity has changed since *person with dementia* moved into long-term care?	If so, how?

Interview Guide – Focus groups

Topic	Question	Probe
Introduction	Tell me about yourself and your family.	How old are you? Where do you live?
Family	What does family mean to you?	
Family	How would you describe your family?	What do you like to do together?
Family	Who is considered your family to you?	
Pictures	Who is in this picture?	Are they your family? What are you doing together in the picture?

Appendix C: Ethical approval

Research Ethics Approval

Research ethics approval