

Stories of Change: Mealtime Resilience of Families Living with Dementia

By

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ABSTRACT

STORIES OF CHANGE: MEALTIME RESILIENCE OF FAMILIES LIVING WITH DEMENTIA

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To date, research delving into the narratives of living with dementia during mealtimes is limited. The methodology used is thematic narrative analysis, following the elements of a 3D narrative inquiry space proposed by Clandinin and Connelly (2000). The purpose was to develop stories by reconstructing participants' experiences to capture insight into how mealtimes change overtime and how adaptations reflect resilience. Two themes and several subthemes were revealed. The first major theme is 'Developing strategies for positive adaptation', with four subthemes including reminiscing, incorporating humour, establishing social support, and having hope and optimism. The second major theme is 'Continuing to learn and adapt', with three subthemes including focusing on the positive gains and personal growth, balancing past pleasures while adapting to the new normal, and accumulating life experiences. This work serves as a basis for future studies examining into the concept of resilience among families living with dementia in greater depth.

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CHAPTER 1: INTRODUCTION

For persons with dementia, change is an ongoing process as their condition progresses. The biological changes from this syndrome lead to brain deterioration and loss of cognitive and functional abilities (Alzheimer's Society of Canada, 2005), impacting the lives of the persons with dementia as well as their care partners (Berg, 2006). In Canada, this common syndrome affects 500,000 Canadians (Alzheimer Society of Canada, 2010) and relatively little is known about how to support older adults through the many changes they experience; more research is needed to gain a better understanding of the disease as well as the way families with dementia adapt and strategize to manage the challenges of their daily experiences. Although stresses and challenges are inevitable when living in families with dementia, the changes experienced as the condition progresses can actually bring positive aspects to the lives of families (Linley & Joseph, 2004).

Eating is often viewed as a time to alleviate hunger and meet physiological needs, often occurring multiple times a day; however, through research the concept of mealtimes has been shown to be more meaningful than merely reoccurring events that happen every day. For example, mealtimes have been found to be a significant time for connecting with one another and honouring identities for families living with dementia (Keller et al., 2010; Genoe et al., 2010). In fact, a study by Keller et al. (2010) found that 'mealtimes mirror the way we are' suggesting that mealtime experiences reflect various aspects of living with dementia, including living with the challenges and joys that come out of the changes experienced as the syndrome progresses.

To date, research delving into the narratives of living with dementia is very limited. There are however, some authors who have written stories about their experiences living with dementia (Bryden, 1998; Davis, 1989; Henderson, 1998; McGowin, 1993; DeBaggio, 2002;

DeBaggio, 2003; Truscott, 2003). Storytelling is a very powerful way of discovering identities and bringing clarity to thoughts and feelings (Ryan, 2006; Kenyon, 1996). By integrating multiple events in a chronological and coherent manner, storytelling is an effective method of expressing this clarity. A study by Ryan, Bannister, & Anas (2007) analyzed published memoirs written by persons with dementia and found that writing stories allowed the authors to create meaning and form identity. Some people may require assistance from others to re-write their words and reconstruct their ideas to achieve clarity (Ryan et al., 2007). Unfortunately, most people will not publish their work and their experience will be left unexplored. In the Eating Together Study, all participants were narrating their stories during each interview. I will use these narratives and reconstruct their mealtime experiences into stories with greater clarity and depth. These stories narrate how families living with dementia maintain connection, find positive meaning and hope to their experiences and establish resilience in their various situations (Egeland, Carlson, & Sroufe, 1993; Duggleby, Williams, Wright, & Bollinger, 2009).

The purpose of this secondary qualitative study is to use thematic narrative analysis to develop in-depth stories of the social aspects of mealtime experiences of families living with dementia, using dyads selected from the Eating Together sample. This will be done by analyzing the participants' stories and rewriting their accounts in a manner that provides depth and chronology into their mealtime experiences. Exploring mealtime experiences over time from different perspectives can improve our understanding of the challenges that dyads face and strategies used to handle these challenges. Taking a different and more in-depth view of these data and reconstructing the data as narrative will provide further richness to our understanding of the mealtime experience with respect to their experience of resilience.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Dementia is a syndrome resulting from various diseases that could lead to diverse disturbances in function, including “memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment” (Langdon, Eagle, & Warner, 2006, pg. 989). These disturbances over time affect an individual’s ability to engage and maintain social relationships or perform daily living activities (Alzheimer Society of Canada, 2010). There is a growing prevalence of dementia at a worldwide level; 35 million people were estimated to have dementia in 2010 and this number is expected to increase to 115 million people by 2050 (Alzheimer Society of Canada, 2010).

Not only do the changes that persons with dementia experience as their condition progresses impact their lives, but they also have an impact on the lives of care partners. The most prominent changes experienced by persons with dementia are decline in memory and communication skills, and these changes require care partners and persons with dementia to adopt strategies in order to utilize their remaining abilities as well as optimizing both parties’ quality of life (Smith et al., 2011). Research on dementia care partners has commonly focused on the negative aspects of care (Pinquart & Sorensen, 2003), however some care partners successfully adapt to changes with hope and resilience (Egeland, Carlson, & Sroufe, 1993; Holtslander, Duggleby, Williams, & Wright, 2005; Robinson, 2005).

Though changes and the adaptation required and the relative success with adaptation vary from family to family, they are reflected through their mealtime experiences, as mealtimes provide a window into relationships and family functioning (Keller, Edward & Cook, 2007; Genoe et al., 2010). The Life Nourishment Theory suggests that “mealtimes mirror the way we

are” meaning that understanding one’s mealtime experience can also help to understand other aspects of one’s experience of living with dementia. This theory offers insight into the importance of mealtimes to families with dementia as a way to be connected, honour identity, and adapt to an evolving life (Keller et al., 2010). A considerable amount of data within the Eating Together study is available to tell us what it is like for persons with dementia and their care partners to live with dementia, including the changes they have experienced and the strategies used to overcome these changes and challenges. Nonetheless, Eating Together researchers have only scratched the surface of the knowledge on the changes experienced over time during mealtimes for dyads; the focus to date has been to develop a substantive theory which necessitates the condensing of deep experience into a few key concepts that are seen in all families and provide a sense of the meaning of that experience. There is a need for research that moves beyond an overview of mealtime experience and examines in-depth longitudinal stories to understand the changes over time in mealtime experiences from diverse perspectives of those living with dementia. Narratives have been used by persons with dementia and their family care partners to provide an in-depth view of their experience and I believe the richness of the Eating Together data can also be used to tell a more insightful story of the mealtime experience.

2.2 Overview of Dementia

Dementia is a common syndrome with growing prevalence, and the cause of it as well as methods to stop its progression remain unknown (Alzheimer Society of Canada, 2009). Although causes are unknown, there are known risk factors that contribute to the cause of dementia, and these risk factors are categorized into non-modifiable and modifiable risk factors. Two known non-modifiable risk factors of dementia include aging and genetics. Some of the known

modifiable risk factors include, but are not limited to, type 2 diabetes, head injury, hypertension, clinical depression, and mild cognitive impairment (Alzheimer Society of Canada, 2009).

The symptoms of dementia are grouped into three stages (National Institute of Health, 2012). In the early stages of dementia, the individual will encounter mild cognitive impairment. Forgetfulness is a common symptom at this stage, where familiar names and location of objects can easily be forgotten. The individual may also experience communication difficulties at this stage, where he or she may have difficulty searching for the right words to express their thoughts. Lastly, friends and family may witness changes in mood and behaviour from the person with dementia. Although cognitive capabilities are starting to deteriorate, people in the early stages of dementia only require minimal assistance because they still maintain many functional capabilities (National Institute of Health, 2012).

In the middle stages of dementia, the person with dementia's cognitive impairment becomes more apparent and functional impairment begins to surface. For example, the person with dementia in this stage may have difficulty with shopping, managing finances, or other complex tasks requiring cognitive and functional capabilities. Hence, persons with dementia at this stage will require more assistance with daily tasks. At this stage, because damage occurs in areas of the brain that control language, reasoning, and conscious thoughts, the capacity for communication and maintaining interpersonal relationship is affected (National Institute of Health, 2012).

In the late stages of dementia, persons with dementia will require extensive assistance in daily tasks because they no longer have the ability to communicate effectively. Their cognitive and functional abilities have deteriorated to the point where they can no longer take care of themselves. Hence, ensuring high quality of life is the major goal for those diagnosed at this

stage. The ability to engage in conversations and interpersonal relationships are highly affected because language is reduced to simple words, eventually leading to loss of speech (National Institute of Health, 2012). These are symptoms that persons with dementia generally experience as the condition progresses, and fundamentally these symptoms will affect various aspects of their experience as they live with dementia.

2.3 Living with Dementia

In general, people with dementia will experience memory loss and impaired judgment during the early stages of this syndrome. As the condition progresses, they lose their independent functioning and must rely on others for continual care (Amella, Grant, & Mulloy, 2008).

Memory, thinking, movement, communication, and planning are just some of the skills needed to engage in the physical and mental activities of mealtime (Barratt, 2004). Considering that mealtime is an activity that involves a number of complex activities which require coordination, the nutritional and social aspects of mealtimes are expected to change as the condition develops.

Besides the documented changes in ability, behavioural changes are also evident among people with dementia. In a small study, care partners identified behavioural changes within people with dementia even before dementia was diagnosed (Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafstrom, 2001). Apathy and social withdrawal are frequently identified among older adults in the early stages of dementia rather than cognitive decline (Derouesne et al., 2002). In other words, social behaviour changes appear to be more noticeable among people with dementia even before diagnosis and can be targeted through interventions to improve their quality of life.

People with Alzheimer's disease also display personality changes, including signs of introversion, disengagement and neuroticism (Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005). Interestingly, they only have a small degree of self-awareness of these changes. Additionally, when asked to report their perception of their personality, this description match their personality before they were diagnosed (Rankin et al., 2005). This may be a result of their cognitive and memory decline as well as changes in judgement and insight.

Behavioural changes were also described among people with dementia during mealtimes, and it was evident that these changes influenced their mealtime experience (Keller et al., 2007). For example, Families with dementia may find it more difficult to dine outside of the home due to behaviours and changes in preference (Keller et al., 2007). Messiness and picking food off of others' plates are some of the common behaviours that families experience with persons with dementia when eating out (Manthorpe & Watson, 2002). Wandering and having difficulty using utensils have also been documented (Anderson & Sidenvall, 2001; Riviere et al., 2002). Apathy and social withdrawal could occur among persons in the early stages of dementia (Derouesne et al., 2002) affecting mealtime conversation. Even though eating out with persons with dementia posed some challenges, it was identified as a way of bringing spontaneity to family's lives (Keller et al., 2007). For example, it was found that there was a sense of enjoyment and pleasure when families dress up and pay attention to their appearance when they plan to eat out (Cassolato et al., 2009). Unfortunately, research to date does not provide an in-depth view of the personal experience of personality and behavioural changes during mealtimes.

Institutionalization typically occurs when there is a loss of functional cognition such as continence (Montgomery & Kosloski, 1994). It is usually a decision made by family care partners, and this decision-making process is described as a difficult experience (Liken, 2001). In

a study by Caron, Ducharme, & Griffith (2006), the process of institutionalizing a loved one was described as extensive; caregivers in the study took an average of two years to make the decision. Some caregivers view institutionalization as a last resort because their loyalty and compassion for their loved one may cause reluctance in their decision (Nussbaum, 1996). Institutionalizing a loved one is often associated with feelings of guilt and shame for being disloyal and uncaring (Nussbaum, 1996). Despite the difficulty of making the decision, sometimes institutionalization may be the most suitable decision for the benefit of the family care partners and the older adult with declining functionalities (Cohen, Shulman, Wortley, McDonald & Wargon, 1993).

Nutritional changes are inevitable among older adults, including persons with dementia. Maintaining adequate nutritional status is important and it has been shown to be directly proportional to their quality of life (Evans, Crogan & Shultz., 2005; Johansson, Bachrach-Lindstrom, Carstensen, & Ek, 2008). Unfortunately, malnutrition has proven to be prominent among this population (Johansson et al.) and the prevalence rate ranges from 12% to 85% (Keller, 1993); weight loss is an indication of dementia (Riviere et al., 2002). Some of the reasons leading to malnutrition among older adults include chewing and swallowing problems, alteration in taste and smell, decrease in cognitive performance, as well as reduction in activity and communication levels (Henderson, 1988; Beck & Ovensen, 2003; Guyonnet et al., 1998; Riviere et al., 2002; Andersson & Sidenvall, 2001). Not only does poor nutritional intake affect quality of life, it can also lead to weight loss, development of chronic disabilities, functional decline, and potentially death (Evans et al.; Beck & Ovensen); dementia compounds the effects of poor nutrition on health. Nutritional issues such as these have been well addressed in current

literature but research has begun to evolve with the focus shifting from physiological aspects to other areas of eating and mealtimes.

Eating and mealtimes involve more than just obtaining adequate nutrition. There are more to mealtimes than the nutrition and the eating behaviour issues often seen that affect food intake. On an abstract level, Aselage & Amella (2009) regard mealtimes as “one of the arts of life” (pg.35). Studies are uncovering the symbolic meanings that are attached to the concept of mealtimes. For some, mealtimes are used to cope with emotions and express feelings, celebrate triumphs, reward hard work, and gain a sense of companionship (Grodner, Anderson, & DeYoung, 2000). For others, mealtime is an activity to maintain family relationship, share their day, and de-stress (Hellström, Nolan, & Lundh, 2007; Fiese & Marjinsky, 1999). Cinotto (2006) investigated the historical perspectives of American family mealtimes and found that Americans believe mealtimes are essential to unite families together because it is considered a social activity that establishes bonds and preserves culture. It was also a time to gather around the table with familiar faces and engage in conversations as well as share familial foods. Along the same idea, another study on participants’ eating and drinking revealed that the activities, social setting, and the mental processes involved in mealtimes have more significant meanings than the nutritional aspects of eating and drinking (Bisogni et al., 2006). Essentially, the concept of mealtimes is more complex than originally believed.

Care partners of persons with dementia also report positive experiences when eating with their loved one. When eating out they noted changing their food choices to accommodate the persons with dementia’s preferences and abilities and also choosing to eat with familiar people (Keller et al., 2007). Positive experiences could be enhanced through mutual support, whether it is physical, psychological, or emotional (Keller et al., 2010). By promoting a time for the family

to become face-to-face during mealtime, the family could participate psychologically even when the person with dementia's ability to communicate is diminished (Keller et al., 2010). Accepting and coming to terms with the changes due to dementia is also a way of showing support as it helps to protect dignity and honour identity of the person with dementia (Genoe et al., 2010). Evidently, not only do the changes experienced by the person with dementia affect themselves, they also affect the people who care for them.

2.4 Changes and Stresses Experienced by Care partners as Dementia Progresses

Care partners strive to maintain a good quality of life for the person with dementia as their condition progresses, but the tasks involved in doing so can cause a lot of stress and burden and it becomes difficult to cope and stay positive (Gaugler, Davey, Pearlin, & Zarit, 2000). In two studies looking at care partner's grief reactions, it was found that reactions varied depending on the functional stage at which the person with dementia was diagnosed (Adams & Sanders, 2004; Meuser & Marwit, 2001). Both studies presented very similar results on care partner's grief reactions in the early stages of dementia. Care partners' grief was based on the losses that were shared within the dyad, such as the activities and the connections that were shared in the past (Meuser & Marwit, 2001). This parallels the results found by Adams (2006), where participants with early stage dementia appear to function normally, but care partners already felt the loss of connection with them.

During the middle stage, care partners continue to experience grief for emotional losses and frustration from their increased responsibilities (Adams & Sanders, 2004). At this stage, the behaviour of a person with dementia can become an issue as their reasoning and judgment change and the level of independence continues to decrease (Gillies & Johnson, 2004). This is

also a stage when care partners report experiencing personal loss, including loss of time, energy, and freedom (Adams & Sanders, 2004). Lastly, sadness becomes prominent and anger subsides as the person with dementia enters the end stage. Even though the person with dementia is alive, the social connection and the interpersonal relationship are described as being lost (Adams & Sanders, 2004). In other words, there is a “social death”, where the person they were is gone but their body is intact; they are perceived as an empty shell with judgment and memory capabilities taken away (Gillies & Johnson, 2004).

One of the shifts in responsibility that care partners must accept is taking over tasks that the person with dementia once performed (Adams, 2006). Though this could initially be frustrating, many care partners gained interest in the new skills they learned to perform (Daniels, Lamson, & Hodgson, 2007). Examples of these instrumental tasks include cooking, housework, and balancing the check book (Adams, 2006). However, it could be difficult to decide how much the care partner should take over while preserving the identity of the person with dementia. A balance between maintaining independence and adjusting to changes is important to honour identity (Genoe et al., 2010). For spousal couples, mealtime is a way to negotiate gender roles (Charles & Kerr, 1988). In a study by Atta-Konadu, Keller, & Daly (2011), it was found that when spousal couples are living with dementia, the healthy spouse is likely to help out or even take over roles previously completed by their partner during mealtimes when the progression of dementia prevents tasks from getting done. For example, the care partner will “slide into food roles” by gradually doing more and more of the food preparation tasks previously done by the person with dementia. The care partner will eventually take over the whole role when the person with dementia loses interest and the capability to perform the mealtime tasks (Atta-Konadu et al., 2011). Role changes become imperative for spousal couples as dementia progresses in order to

survive as a unit; it is however identified as a challenge (Russell, 2007), especially when the care partner is forced to learn to perform a role without previously acquiring these skills, such as cooking. The above research provides a perspective of gender roles during mealtimes, a lens to a particular situation. It is anticipated that with further in-depth analysis of a specific family, the experience of the dyad during the process of change and specifically role changes could be further understood.

Caregivers' increasing amount of involvement in the life of the person with dementia has been found to be quite common as role changes occur. Findings in a qualitative study by Chung, Ellis-Hill, & Coleman (2008) discovered that care partner's level of engagement developed as the person with dementia's condition progressed. The level of engagement was based on the person with dementia's five activity patterns: 1) usual pattern, 2) recognizable pattern, 3) illogical pattern, 4) irresponsible activity pattern, and 5) dispossessed activity pattern. The 'usual pattern' describes the person with dementia's normal functioning and the care partner's usual involvement in the relationship. Recognizable pattern is described as the person with dementia's occasional unusual functioning and care partners use of everyday activities to assess their declining abilities. Illogical pattern reflected a time when care partners noticed significant changes in the person with dementia and used encouragement to re-engage them in everyday activities. This is also a time when care partners question their capacity to compensate for the significant changes seen in their spouse. Irresponsible activity pattern is when the care partners acknowledge that the person with dementia could no longer perform self-care activities and take responsibility for their own actions. At this time, care partners adopt the added roles and responsibilities as well as managing the daily routines. Lastly, the dispossessed activity pattern represents a time when the person with dementia has total dependence on the care partner for the

majority of everyday routines. Ultimately, the care partner's involvement in the dyad relationship is the highest at this time but continues to engage the person with dementia in daily activities as much as possible (Chung et al.). Research on changes and stresses that care partners experience tends to have predominantly focused on the negative aspects of care and functional loss (Pinquart & Sorensen, 2003), however resilience and hope can also exist.

2.5 The Journey from the Perspective of Care partners as Dementia Progresses

To deal with the inevitable stress that results from continual change, care partners have developed various strategies to not only maintain a good quality of life for the person with dementia, but for themselves as well. A study by Farran, Loukissa, Perraud, & Paun (2004) investigated the strategies used by care partners caring for those with Alzheimer's disease. Five major categories of strategies included: 1) dealing with change, 2) managing competing responsibilities and stressors, 3) providing a broad spectrum of care, 4) finding and using resources, and 5) experiencing emotional and physical responses to care. Dealing with change refers to adaptation to the change in lifestyle, roles, and goals that care partners commit to as uncontrollable changes occur. Managing competing responsibilities and stressors is a result of realizing the added responsibilities that have been placed in front of them and learning to balance and incorporate the workload into their other daily activities. Adopting an intuitive sense for the person with dementia's needs and changing behaviour can assist care partners in providing a broad level of care while acknowledging their remaining strengths and abilities. Seeking external resources and being open to available services is another strategy when stress becomes unbearable. Lastly, being able to acknowledge the emotional responses associated with being a care partner is an important strategy to manage their own physical wellbeing. As dementia

progresses and changes develop, these strategies are not used in any particular order but are used in conjunction with each other for care partners to become more skilled (Farran et al., 2004). Even though five main strategic categories were developed, the changes encountered and the methods each care partner used to realize these strategies in this study were different hence making each of their experiences unique.

A study on daughters' experiences on caring for mothers with dementia identified different strategies in response to care giving (Perry, 2004). The three main categories included: (re)calling, (re)learning, and (re)adjusting. Interestingly, the use of "re" as a prefix represented the deconstruction and reconstruction of the daughters' knowledge of their mothers as changes continually occurred around them. In (re)calling, daughters are recalling the memories of the mother they used to know and identify the changes and inconsistencies based on their current observations. In (re)learning, daughters are rediscovering the "current" mother and how to reconnect with them, while in (re)adjusting, daughters reflect and make sense of the changes and make adjustments for the protection of themselves and their mothers. These categories provide a specific strategy of utilizing previous knowledge and building on to it based on the observed changes.

From a social interaction theorist's perspective, gaining an empathetic view of the person with dementia by standing in their shoes can develop respectful care (Blumer, 1969). When care partners envision the experience of living with dementia, their emotional responses allow them to view the person with dementia as one who needs to be connected with, rather than a dispossessed body that requires task-oriented, custodial care. Understanding this perspective is another strategy that care partners may use to become effective care partners who can help people with

dementia regain social connection, but also value the meaning of the connection, such as the value of social interaction during mealtimes.

Although there is limited research on mealtime strategies, a study by Keller et al. (2007) explored the family perspective of mealtime experiences of families with dementia and their strategies to encourage a pleasurable dining experience. Changing eating routines to accommodate the person with dementia's changing needs was a common strategy used to preserve the social connection at the table. Not only do eating routines need adjustments, but the simplification and size of meals also required modification. As the person with dementia's food preferences altered and appetite shrank, it was often difficult for care partners to produce palate-pleasing meals three times a day that they were also willing to consume. When stress became overbearing, seeking alternatives was another way of coping with the changes, such as eating out at a restaurant to avoid cooking. Although stress and challenges were involved in mealtimes with persons with dementia, care partners continued to adopt strategies to cope because they saw the value in preserving the traditions of eating together and maintaining the social experience (Keller et al., 2007).

The process of mealtime changes as dementia progresses and it is necessary for care partners to discover new strategies to adapt to these changes. In other words, care partners need to restructure their life and plan around the changes that occur and reorganize priorities (Silva-Smith, 2007). It was found through the Eating Together Study that care partners adjusted to mealtime changes by: 1) being aware of the change, 2) attaching meaning to the change, and 3) responding to the change (Genoe et al., 2012). Dyads were able to transform when they were able to accept and adapt to the changes. This is an active process of understanding the changes and discovering strategies to accept and overcome them (Keady & Gilliard, 1997). However,

changes are difficult and could readily be resisted by some dyads as well (Genoe et al., 2012). Resistance is likely temporary because dyads eventually learned to adapt as changes continued to progress.

It would also be beneficial to discover narratives looking at the perspectives of care partners' journeys, although published accounts are very limited. Markrut & Crane (2005) combined anecdotes shared by multiple dementia caregivers. Though the narratives presented the challenges they had experienced and the strategies they used to overcome those challenges, the stories also shed light into their changing perspectives as they moved on in this journey. For example, Bob, whose story is explicated in Markrut & Crane's account, realized that despite the hardships of coping in a family living with dementia, he learned a lot about himself and the importance of spending time with family rather than placing focus on his job. Similar to other caregivers in this study, he had grown in maturity and capacity to appreciate the greater things in life. Something that a lot of caregivers touched on in this study was valuing the connection with the person with dementia. Markrut & Crane referred to this connection as a 'compassionate connection', which refers to the memorable and gratifying connections established with the persons with dementia, considering that the persons with dementia are only able to experience and express the present moment. For some, it was a connection that was not present prior to the diagnosis, but the progression of the illness allowed the persons with dementia to become more open and affectionate. With the remaining treasured period to enjoy, caregivers such as Robert Tell (2006) learn to push aside the irritations and embrace the gentleness of connecting with his mother.

To date, how strategies change over time during mealtimes has yet to be explored. While it is evident that there are studies which explore the coping strategies used by care partners, there are also studies that discovered coping strategies used by persons with dementia.

2.6 The Journey from the Perspective of Persons with Dementia

Studies on understanding the journey from the perspective of persons with dementia and the strategies they use to cope are limited because of the perception that persons with dementia could not provide accurate accounts due to their cognitive disability, and that their interpretation of their lived experiences were unreliable (Pearce, Clare, & Pistrang, 2002). However, some studies have included the perspectives of coping with dementia through the eyes of those who were experiencing it.

Prior to a diagnosis of dementia, persons with dementia noticed preliminary changes such as short-term memory loss or cognitive impairment (Adams, 2006). They detected the need to ask for clarification and guidance (Gillies, 2000). A study by Clare (2002) identified stages that persons with Alzheimer's disease used to cope with their diagnosis and how their strategies evolved as their condition progressed. The four identified stages included: 1) holding on, 2) compensating, 3) fighting, and 4) coming to terms. Holding on refers to the struggles of preserving the normal standard and overcoming the detected changes (Clare, 2002). When there was a growing uncertainty about themselves, it could conflict with their self-awareness and self-esteem (Gillies & Johnston, 2004). A common strategy to avoid causing losses to their self-esteem was to avoid situations where their memory was challenged (Gillies, 2000). Additionally, when responsibilities were taken away from them due to their cognitive decline or memory loss, it could cause a sense of role erosion that could further injure their self-esteem (Gillies &

Johnston, 2004). Compensating, which refers to the realization that they would become continually dependent on others and feel resentful for their reliance, was next identified (Clare, 2002). Examples of strategies used to compensate for their memory loss included the use of memory aids including diaries, alarms, and coloured labels. Identifying stages that persons with dementia go through during mealtimes, similar to what has been described by Clare (2002) would give a perspective on how the progression of dementia affects mealtime activities over time.

Those that had a strong will could choose to put up a fight by learning more about the disease and preserving what they had left. Actively engaging in fighting to keep their sense of self-identity was common among those living in the early stages of Alzheimer's disease (Beard, 2004). Eventually most of the persons with dementia gain acceptance of their situation and come to terms with their reality while maintaining a level of optimism (Clare, 2002). In other words, coming to terms is a stage that created a balance between hope and despair within their reality (Clare, 2002). This was also common among most of the participants in another study (Gillies, 2000) where persons with dementia accepted what was beyond their control and sought effective approaches to face the challenges ahead. For example, one of the strategies often used to preserve a sense of dignity and purpose was to remind themselves that there were others that were less fortunate, thus creating an appreciation of what they still had (Gillies & Johnston, 2004). On the contrary, those that did not acquire a fighting spirit had a more pessimistic outlook on their situation, and perceived themselves as a burden or someone who had lost their social value (Gillies & Johnston, 2004). For those that did not have the strength to thrive they may eventually become institutionalized.

Perspectives of persons with dementia's journey could also be obtained through narratives, though published accounts are limited. The four stages suggested by Clare (2002) can be witnessed in some of these available published narratives. For example, Robert Davis (1992) illustrated his frustration and fear for his diminishing memories and abilities upon diagnosis of Alzheimer's disease. However, his faith in God, support from his wife, as well as his circle of friends restored his appreciation for life, despite the challenges he needed to face. Positive realizations were also demonstrated in Diane McGowin's (1993) life story. She initially experienced increasing isolation, leading to doubts of her existence and identity. She eventually came to terms with her condition and concluded that if she possessed emotional and tactile senses and was able to respond to her surroundings, she was existing, and she strongly believed her existence was of inherent value. It was commonly seen in these narratives that the authors rediscovered themselves, and developed a greater awareness for the 'silver lining' to this illness as well as appreciation for those that gave them meaning in their lives. Bryden (1998) and Truscott (2003) also learned to focus on enjoying the moment and living life more fully. Bryden (1998) viewed dementia as a gift; it gave her the free time to pick up her daughters after school, admire the beauty of a sunset, and hugging her husband. She also viewed her journey of dementia as a dance, where her husband would guide her every step on the dance floor, liberating her from making tough choices while retaining dignity (Bryden, 1998). Truscott (2003) learned to treasure every moment of every day and push aside the disappointments and anger she was once consumed by. This included trying new things without worrying about failures and mistakes. The most important recognition among all the authors was that they were not alone in this illness. Care partners, family, and friends walked alongside them through their journey with dementia.

At this time, there are no narratives looking specifically into the mealtime experiences for families with dementia. The way the authors present their life stories can provide an in-depth perspective into the experiences of living with dementia that brings readers into a different dimension of this journey.

2.7 What is the Mealtime Journey like for Families Living with Dementia?

Numerous studies have shown that providing an engaging social environment for people with dementia and improving the quality of interaction within the feeding relationship can lead to a positive influence on nutritional intake (Wright, Hickson, & Frost., 2006; Amella, 2002; Barratt, 2004; Wikby & Fagerskiold, 2004). Likewise, a study looking at the influence of social engagement for nursing home residents found that residents who were less socially engaged scored lower in activities of daily living (ADL) and cognitive functioning, and were at higher risk of chewing and swallowing problems (Beck & Ovensen, 2003). Considering the functional losses of living with dementia, this population can greatly benefit from social interaction during mealtimes.

Not only does social interaction benefit nutritional intake, it is also a way of promoting connection with one another, whether it is physically, emotionally, or psychologically (Keller et al., 2010). At any stage of dementia, mealtimes are viewed as the “highlight of the day” (Keller et al., 2007) and the relationships that are formed and maintained during this multipart event are deemed to be critical and meaningful to their social lives (Amella, 2004). For couples living with dementia, mealtimes involved shared activities to stay engaged with one another (Hellström, Nolan, & Lundh, 2005). For institutionalized older adults, it was found that mealtimes were one of the main reasons why residents looked forward to leaving their rooms and socializing with

their neighbours (Bryon, 2008). Not only is socializing with neighbours important at mealtimes, but this social interaction with staff is also deeply valued (Ruigrok & Sheridan, 2006), because they are no longer isolated but in a dining room with company (Bryon, Dierckx de Casterle, & Gastmans, 2008). This is especially important for institutionalized residents because they have been located into a new place with a decline in familiar connections (Dupuis-Blanchard, Neufeld, & Strang, 2009).

Unfortunately, not all residents receive the social interaction they need. Social withdrawal can occur in early stages among persons with dementia (Derouesne et al., 2002). In later stages, Ryvicker (2009) observed that nursing assistants did not routinely engage in conversation with residents, and this was especially apparent during mealtimes. Nursing assistants often spoon feed residents while standing up, meaning the nursing assistants are out of range of residents' vision and there was a lack of a the physical connection. Furthermore, nursing assistants often converse with each other, talking over the residents' heads, thus segregating residents from their conversation and not allowing for connection to be established (Ryvicker, 2009). Health professionals need to gain a better understanding of the social needs of older adults, rather than holding onto the misperception that residents are incapable of maintaining meaningful social relationships (Ryvicker, 2009) and are thus not worthy of social engagement.

According to Amella, Grant, & Mulloy (2008) who have created interventions for people with moderate to late-stage dementia, the ultimate goal for persons with dementia is to enhance their mealtime experience and quality of life, be able to preserve their independence and dignity, engage them in social interactions, and give meaning to every meal. Mealtime is a vehicle to maintain and reaffirm identities (Dowler & Leather, 2000; Fischler, 1988; Genoe et al., 2010; Lupton, 1994; McIntosh, 1996). This is especially important for persons with dementia because

they are more susceptible to loss of their roles and statuses (Cheston & Bender, 1999; Genoe et al., 2010).

The importance of mealtimes was further elaborated by Keller et al., (2010) through the Eating Together Study, a qualitative project which explored the mealtime experiences of families with dementia. The Life Nourishment Theory was developed through this study which incorporates three inter-related concepts: being connected, honouring identity, and adapting to an evolving life. Being connected refers to connecting physically, psychologically, and emotionally with each other during mealtimes (Keller et al., 2010). This guaranteed time allows dyads to bond through mealtime tasks or engage in casual conversations. Honouring identity refers to promoting and respecting each other's unique identities during mealtimes. Protecting dignity and recognizing remaining abilities are ways of respecting one's identities (Genoe et al., 2010). Adapting to an evolving life refers to the process of being aware, adjusting, and adapting to the changes experienced during mealtimes as dementia continues to progress (Genoe et al., 2012).

The Life Nourishment Theory along with other studies focusing on the psychosocial aspects of mealtimes brought our understanding on the importance of mealtimes to a higher level. It is evident that the concept of sharing meals is a vehicle for families to negotiate gender roles and promote bonding time (Charles & Kerr, 1988). However, the specific mealtime journey experienced by a family living with dementia has yet to be uncovered; it is anticipated that by retelling this journey using thematic narrative analysis, the meaning of mealtimes will be further elucidated. Currently, there is a lack of longitudinal studies in this area of research and we do not yet have a holistic and in-depth understanding on how the mealtime experience changes for families with dementia. I hope to gain a clearer understanding how families with dementia adapt to mealtime changes and the stories they tell in this mealtime journey. There are also no

narratives looking directly into the developing process of being resilient during mealtimes as families live with dementia. While it is already known that living with dementia is full of changes and stresses and resilience has been demonstrated, how families become resilient during mealtimes specifically can be further researched so families could positively adapt.

2.8 What is Resilience?

Having resilience is being able to positively and successfully adapt to stressful experiences (Egeland, Carlson, & Sroufe, 1993). Resilience was once thought of as a post-adversity strength (Wilks, 2011). This is contrasted with “coping”, which is a durational strength that occurs during adversity to reduce or remove negative factors in life (Endler & Parker, 1990). The contrasting definition of being resilient and coping was modified in 2002 by Kralik, to resilience being a form of successful self-management to bring order, discipline, and control in an individual’s life. This was contrasted with coping, which is being in a state of tolerating, minimizing, or ignoring something that cannot be faced or mastered (Richardson & Poole, 2001). Although resilience was once described as a personal attribute and an outcome, it is now better interpreted as a dynamic process (Ryff & Singer, 2008). That is, because resilience needs to be developed, and if an individual has never been exposed to any threats or adversities, they cannot be described as resilient (Masten, 2001). Ryff (2012) specifically defined the capacity to maintain or retain psychological well-being when facing challenges as psychological resilience. Therefore, if physical health and psychological well-being could be maintained or regained during the presence of life challenges or adversities, one is considered resilient (Resnick, Gwyther, & Roberto, 2011). Someone being resilient holds the mindset of “what does not kill me makes me stronger” (Smith, 2012).

Some research has focused on determining reasons why some people have the ability to overcome adversities in their life, while others succumb to critical life events (Hildon, 2008). Some determined that there are three major protective factors that help an individual to be resilient, including individual attributes, quality interpersonal relationships, and environmental supports (Goldstein & Brooks, 2005; Ong et al., 2009; Vanderbilt-Adriance & Shaw, 2008). Others determined that part of being able to adapt to such stressful situations is to have hope (Snyder, 2002), which involves using inner strength to find the positive side in any situation and see that when they look on the “brighter side”, possibilities become more apparent (Duggleby et al., 2009). Those who have greater hope also have a greater ability to find the meaning and even benefits of their illness (Linley & Joseph, 2004). Another way that people demonstrate resilience is to draw on social resources to manage adversity, such as relying on supportive relationships (Hildon, 2008). Relationships were found to be a significant factor to having a sense of being valued, feeling secure and developing a connection with other people thus leading to becoming resilient (Kralik, 2006). It is claimed by Deveson (2003, p.151) that deep connection is the most important prerequisite for resilience or else families become emotionally impoverished. Kralik (2002) noted that to determine the strategies needed to be resilient, it is necessary to do the following: recognize and monitor boundaries, mobilize resources, manage the shift in self-identity, and lastly balancing, pacing, planning and prioritizing their lives (Kralik, 2002).

2.9 Resilience in Families as Dementia Progresses

Specifically for care partners of persons with dementia, hope has been found to be a key psychosocial resource to balance the daily stresses and maintain a sense of wellbeing (Irvin & Acton, 1997; Borneman, Stahl, Ferrell, & Smith, 2002). With hope, care partners can accept and

come to terms with the situation by acknowledging the changes that the person with dementia is going through and recognizing that they are doing their best to provide care for the person with dementia (Duggleby et al., 2009). Persons with dementia who have hope and resilience also have a positive attitude towards the social aspects of aging (Wolverson, Clarke, & Moniz-Cook, 2010).

As couples, dyads living with dementia also need to demonstrate considerable resilience to maintain quality of life. Examples of doing so include maintaining a positive attitude, holding on to simple pleasures, and treasuring the present moment (Hellström, Nolan, & Lundh, 2007). A way of maintaining a positive relationship is to avoid taking hurtful events personally and acknowledging that the problem stems from the disease itself (Genoe et al., 2011). When living with dementia, changes are inevitable and couples must continuously incorporate changes while holding on to routines that do not require changing, such as taking walks together (Robinson, Clare, & Evans, 2005).

Resiliency among families with dementia was also demonstrated within the Eating Together Study (Genoe et al., 2010). It was found that mealtime is a time for families to respect each other's uniqueness and protect dignity while changes occur. Acknowledging each other's preferences and choices is a way to respect uniqueness. Negotiating capacity and maximizing each other's abilities and roles is a way to protect dignity (Genoe et al., 2010). Not only will sharing activities help to contribute to the household, it is also viewed as a way of reinforcing relationships (Hellström, Nolan, & Lundh, 2005). This is especially important for dyads living with more advanced dementia because mealtimes may be the only time the person with dementia is alert enough to engage with others (Keller et al., 2010). Mealtimes therefore become a potential time for positive interactions to occur (Keller et al., 2010). Adding on to this research, it

would be helpful if more could be offered on how these positive interactions change as dementia progresses from early to later stages.

2.10 Theoretical Frameworks for Change and Resiliency

The continual change and resiliency experienced by families with dementia can be guided by two theoretical frameworks: the Thriving model and the Family Adjustment and Adaptation Response (FAAR) model. These models can help us to better understand how change happens and what change is like for families living with dementia during mealtimes.

The Thriving model provides a holistic view to study people's life span as they age (Haight, Barba, Tesh, & Courts, 2002). It is a continuum spanning from the two extremes: complete failure to thrive and perfect thriving. Failure to thrive is when there is disengagement among the person, human environment, and nonhuman environment. Seven attributes of failing to thrive include "disconnectedness, inability to give of oneself, inability to find meaning in life, inability to attach to others, consistent weight loss, depression, and decline in cognitive function" (Newbern & Krowchuk, 1994, pp.16). On the other end of the spectrum, thriving is where there is harmony and engagement between the person, human environment, and nonhuman environment (Haight et al., 2002). Having the ability to thrive means being able to 'flow' with the changes that happen in life. There are many variables within the person, human environment, and nonhuman environment that affect the way individuals thrive through life. Contributors such as positive attitude and family support can enhance an individual's way of thriving; whereas detractors such as poverty and negative attitude can send one towards failure to thrive (Haight et al., 2002). In addition, peak or valley experiences can send a person to an extreme end of a continuum. Researchers suggest that by depicting an individual's experience

across the life span, a story can be constructed (Haight et al., 2002). This theory was relevant to my work because it provided a basis on exploring the stories of change that families with dementia experienced throughout the time of living with dementia.

The FAAR model suggests that families try to maintain homeostasis by meeting continuous demands using their abilities or external resources (Patterson, 1988). The meanings that the family assigns to the changes are a critical factor in achieving balanced functioning. This model contains two phases: adjustment and adaptation, with family crisis in between. The adjustment phase refers to a stable period of meeting demands for minor changes that have occurred. A crisis occurs when the number of demands outweighs the family's ability to meet the demands. During the adaptation phase, the family discovers strategies to achieve a balance, such as utilizing additional resources, reducing demands, and/or changing their attitude towards the situation (Patterson, 1988). Going through these two phases gives families a chance to learn and grow from each crisis situation, becoming more resilient to living with dementia. In this model, there is an emphasis on looking at the family's response to the adjustment-crisis-adaptation cycle over time. This coincides with the purpose of this study to look at what the mealtime experience is like over time for families with dementia. Essentially, the changes that families encounter during mealtimes serve as demands. How they achieve balance and become more resilient with the mealtime changes can be reflected through their adjustment and adaptation phase.

2.11 Summary of Literature Review

The stresses and challenges that come along with living with dementia have been well documented in current research for many families' journeys. More research is needed on exploring strategies to help strive for successful and positive adaptation. The impact of mealtime

experiences for families living with dementia has been found to be significant to their physical, emotional, and psychological well-being, therefore it is worthwhile to conduct further research specifically on how families living with dementia develop and strive for resilience during mealtimes.

Respecting each other's uniqueness, maximizing each other's abilities, and sharing activities are some of the ways that families living with dementia incorporate positivity and reinforce relationships during mealtimes. Thematic narrative analysis, a methodology that is not commonly used in the field of nutrition, may help to determine additional strategies and reach audiences in a more engaging manner than work conducted to date.

CHAPTER 3: RATIONALE AND RESEARCH

Mealtime is a complex phenomenon that holds multiple meanings including eating for health, pleasure, as well as for social connections and development and maintenance of identity. For families living with dementia, these aspects of mealtimes have been shown to be important and there is a greater understanding of the psychosocial aspects, with thus recent research focus (Keller et al., 2007). However, available research on this area of study has been for the most part cross-sectional and has limited the capacity to fully capture the depth and meaningfulness of mealtimes. By exploring the mealtime resilience of families living with dementia through a longitudinal study, a greater understanding is reached of the individual experience that occurs over time. Numerous studies have already documented the general changes and experiences that families with dementia encounter over time; their strategies, challenges and resilience that are shown. The Life Nourishment Theory from the Eating Together study identifies that mealtimes reflect ‘the way we are’ (Keller et al., 2010; Genoe et al., 2010; Genoe et al., 2012). Essentially, the changes experienced at mealtimes reflect everyday life and vice versa. This core category describes how mealtimes reflect the day-to-day life of families with dementia, the challenges, trials, ways of interacting, approaching problems, and celebrating joys. Essentially, by exploring the changes that occur during mealtimes for families with dementia, we gain access to a perspective of their lives overall. A more in-depth study focused on the stories told by families over time could enhance our understanding of the journey of living with dementia as well as a greater understanding of the meaning of mealtimes to families.

Using narrative analysis, I will address the following research question:

What are selected participants’ stories of how mealtimes change over time, and how do mealtimes reflect their resilience?

Sub questions:

- 1) How do participants experience the process of dealing with change, from encountering a problem, struggling with the problem, and overcoming/being defeated by the problem?
- 2) What are the common turning points and major events that trigger change in participants' mealtime experiences? What do these major changes mean to the participants?
- 3) What specific strategies do families with dementia use to respond to the change? How did the use of strategies change as dementia progressed?

CHAPTER 4: METHODOLOGY

4.1 What is Narrative?

Narrative inquiry serves as a bridge to connect the art of literature and the science of research practice (Daly, 2007). Narratives are stories interpreted by people of various backgrounds to reveal truths about human experiences (Riessman, 2007). A narrative analysis can include multiple stories featuring characters sharing developmental experiences (Frank, 2010). Telling stories is also a way for storytellers to imitate and make meaning out of their reality. At the same time, stories have the ability to build excitement, expectations, and even anxiety for listeners. These stories are organized chronologically from the past, then the present, and then to the future using specific events or experiences to build to a conclusion or to explain a situation (Daly, 2007). Essentially in narrative, ‘one thing happens in consequence of another’ (Frank, 2010, p. 25). In a narrative perspective, research participants during interviews become authors of their own stories and even co-authors of the same stories during dyad interviews. Participants’ collective accounts of their experiences construct images of plots and scenes, characters and identities. Narrative inquiry allows researchers to present experience in a holistic way while incorporating its richness and complexity (Webster & Mertova, 2007); this makes narrative analysis a suitable method for this study because I can present a holistic picture of the changes experienced by families with dementia during mealtimes while integrating the complexities and meanings of these changes over time.

4.2 Thematic Narrative Analysis

The data analysis methodology that will be used for this study is thematic narrative analysis (Labov & Waletzky, 1967). The purpose of this research methodology is to analyze

participants' stories in depth and reconfigure them in a manner that is chronological and sensible (Creswell, 2007). In other words, not only are participants telling stories, but researchers are also constructing stories from the gathered data. This methodology is ideal for capturing the specific life stories of one or a small number of participants (Riessman, 2007). Chronology of narrative analysis is a factor that makes this methodology unique (Creswell, 2007). Researchers realign the memories of the past, current experiences, and foreshadowed future and interpret different aspects of the lived experiences (Riessman, 2007).

In retelling the participants' stories, I will be accumulating 'puzzle pieces' that represent preserved details of their stories and assemble them into a holistic picture that reflects the changes in mealtime experiences over time. It is important to note that I would not be able to capture every aspect of participants' experiences nor would I be able to capture all the changes experienced throughout their life. Hence, I am assembling a panoramic puzzle with no end pieces on the left and right side because changes may not have been captured earlier on in their lives and future changes have yet to be anticipated.

4.3 Paradigm and Epistemological Position

The paradigm that informs my research is social constructionism a framework introduced by Kenneth J. Gergen in 1985 (Liebrucks, 2001). This paradigm suggests that social phenomena are created through social interactions. Sabat and Harre (1992) further define this paradigm and suggest that the construction of the social selves involves social and dialectical interactions, and therefore relies on the cooperation of others (Sabat and Harre, 1992). This paradigm identifies that reality is a subjective meaning-making process, therefore the external reality is perceived

subjectively by the observer that understands it (Daly, 2007). Given the subjective nature of the meaning making process, there is potential to have reality represented in various ways.

Considering my strong view on the subjectivity and the multi-dimensional state of being, I am taking an interpretivist stance as my epistemological view; I believe that knowledge is created through the subjective meaning making process in one's mind (Daly, 2007). Through this view, I acknowledge that the nature of knowledge is not accurate and certain, but rather it is open for multiple viewpoints and interpretations (Daly, 2007). My values and experiences as a researcher may have an influence on the way I approach the analysis. As an ontological standpoint, I position myself according to the idealism paradigm, where reality is acknowledged through the human mind and meanings that are communally developed (Snape & Spencer, 2003). This paradigmatic framework complements well with the theoretical framework that has informed this research. Narrative analysis and the restorying of the mealtime journey told by persons living with dementia and their partners in care fits with my ontological and epistemological stance.

4.4 Issues in Using Secondary Data Analysis

There are several issues with using secondary qualitative data. Firstly, my limited contact with the participants and exposure to the interviews may have caused potential errors in coding and I may have considered something a key idea that the original researcher and/or participants may not have considered to be significant in the investigation (Thorne, 1994). Also, owing to the fact that I have not interviewed the selected families, I may not be able to grasp the experiences portrayed during the interview in their entirety; my interpretation of the interview transcripts may have differed from what the participants meant to say. I was fortunate to have

had the opportunity to have access to the original researchers, which allowed me to retrieve additional data to make sense of variations (Thorne, 1994). To maximize my knowledge of the change in mealtime experience of the selected families, I used the experience of the interviewers who were part of my committee to reflect on if my restorying was consistent with the voices of the chosen families. Lastly, as with any qualitative research, experiences, values, and priorities affect a researcher's perspective (Charmaz, 1990). I acknowledge that my bias influenced the analysis and with this secondary analysis there is the potential that they were intensified (Swanson, 1986).

4.5 Data Analysis and Interpretation

4.5.1 Selection of Families

Before selecting specific families for this study from the Eating Together study, I had to become familiar with some of the families in order to determine which would be most suitable for my study. Families deemed eligible to include in this secondary data analysis were those that demonstrated various changes throughout their years of participating in the Eating Together study. Members of my committee, of which two were investigators on the Eating Together study, had narrowed this down to five families for me to review with the recommendation that I identify approximately two families to include in my study. It was mutually agreed among the committee that two families would be a suitable number to include, such that I would be able to spend enough time with both families to capture the detailed story of their mealtime experiences over time.

After being exposed to several interview transcripts and discussion with the committee, it was agreed that Dyad 12 and Dyad 23 would be included in this study due to their unique and

divergent stories of the mealtime experience over the course of participation in the Eating Together study. These dyads were specifically chosen to show diversity in relationship and adaptation to mealtime changes, their involvement for at least four of the six years of the study, and their capacity with storytelling. Furthermore, Dyad 23 presented a slower progression of dementia and a more positive story of resilience, even with long-term care admission, while dyad 12 struggled with a more rapid progression and a more negative transition experience, and finally the death of the person with dementia.

4.5.2 Data Analysis

Upon obtaining permission to conduct this study from the University of Guelph Research Ethics Board, I chose to follow the procedures proposed by Creswell (2007), as a general guide to conduct a thematic narrative study.

Before conducting any data analysis, I explored various ways that thematic narrative analysis could be conducted. I looked at manuscripts that used this methodology as well as reading books that described this methodology. I found that some manuscripts were written in an autobiographical manner, but I felt this method would not be as effective for me because I conducted secondary data analysis, where there was a barrier between myself as a researcher and the participants. I also found some manuscripts that had written several short stories so each story represented one theme. I decided that would not be effective for my research because I needed to explore mealtime resilience over time, and longer stories with multiple themes would better demonstrate the changes in resilience over time. Based on reading various transcripts and learning about thematic narrative analysis, I have conducted my study in a manner described below. The first step after choosing the participants was to gather all the available data that were

produced based on the selected families. This included interview transcripts, reflections, and coding memos written by interviewers. All the available data were secondary data, which originated from the Eating Together study. As new questions emerged in my analysis, I took on the role of re-examining the data looking for new insights. In other words, I analytically expanded this work by making additional use out of the original data to answer new emerging questions that were sufficiently close to the original research (Thorne, 1994).

The second step was to detect key elements of the told stories, such as the time, place, and plot and then to reorganize these into a concise retelling of the story. As with any story (Frank, 2010), talk that has the characters describing a problem, their struggle with the problem and its resolution, either through, change in themselves, adaptation or defeat was specifically looked for as a basis for restorying. These key elements were organized so that the story could be rewritten in sequential order. Since thematic narrative analysis focuses on the content of the speech, rather than how the story was told, the spoken language was transformed to make sure the content was easily understood (Riessman, 2007).

When analyzing the plot, I chose to follow the elements of a 3D narrative inquiry space, proposed by Clandinin and Connelly (2000). This process involves detecting three dimensions of the story. The first dimension is the interaction, which involves looking inward and outward in to the personal and social interactions that participants engage in based on their stories. The second dimension is the continuity, which involves looking backward and forward into the past, present, and future of the story. The third dimension is the situation, which involves attending to the place in which the stories were lived and told. After obtaining a 3D analysis of participants' stories, I then retold the stories by reorganizing the data in a way that made sense. I worked with a single interview at a time, and reorganized relevant episodes chronologically (Riessman, 2007). An

example of visually looking at the first dimension is to draw a map to illustrate the interactions that are involved in the lives of the participants. An example of reorganizing the continuity of data is to create a timeline of events that demonstrate change when living with dementia. During the process of detecting these elements and dimensions, and retelling their story in a more succinct way, I detected common ideas and links that became initial codes for themes. Besides analyzing for chronology, turning points, epiphanies, or any major events and experiences were also noted for each story.

After retelling the story, I turned to thematic analysis to identify common themes of resilience between the dyads. The third step was to sort the initial codes into potential themes. I loosely followed thematic analysis guidelines proposed by Braun and Clarke (2006) for this step. Ideas that appeared to be important for participants and posed as a pattern across dyads became a theme. The fourth step was to review and refine the potential themes depending on if the theme was significantly brought out in the story to support them. Refining involved determining the validity and strength of the themes. I reviewed the themes to ensure they strongly represented the selected families' change in mealtime experiences and those that represented resilience. The fifth step was to clearly define the themes and provide each with labels that effectively described the essence of the themes. Subthemes were created for further refinement of the themes and a diagram to illustrate these themes was developed. Finally, the sixth step was to search for vivid examples from the data set that captured the essence of each code and theme. As the restorying already provided a sense of these themes, this section was relatively brief.

4.5.3 Rigour

4.5.3.1 Reflexivity

Every researcher has their unique methods of shaping the findings based on their personal, cultural and social politics that they bring to research (Creswell, 2007). It has been widely acknowledged that it is fundamental for researchers to be reflexive during the process of creating meaning in qualitative research in order to address and control our biases (Mauthner & Doucet, 2003). Reflexivity is the process of continuously being aware of how our personalities and experience have an effect on what topic we want to focus on, how we shape our questions, and how we interpret our data (Daly, 2007). Essentially, it is a method of critically examining and understanding our role as a researcher and the level of impact we have when conducting our research. It is inevitable that our perspectives, experiences, and biases will play a role in the research because the results are co-constructed between the researchers and the participants (Creswell, 2007). The research outcome is essentially a representation of the interaction between the researchers and those being researched. Even though the researcher has their own interpretation of the results, readers may create their own interpretations that differ from the researcher and even the participants (Creswell, 2007).

Throughout my data analysis process, I was reflexive by being aware of my own perspective and how it impacted my interpretation of the data. I also kept a record of my thoughts by jotting notes on the side of transcripts to keep track of my potential assumptions. This method helped to document how my experiences and biases of mealtimes for persons with dementia had an effect on my data analysis. As a former personal care aide at a nursing home, I had witnessed the behaviours of residents living with moderate and severe dementia. I not only witnessed the challenging behaviours that can occur at mealtime, but also listened to their stories

that they enjoyed retelling again and again. Even though reminiscing and social support were prominent resilience strategies I had witnessed, I had to put aside my experiences and be more open minded about other strategies that may be demonstrated by participants in this study. Also, similar situations I had experienced in the past cannot be automatically linked to a similar situation experienced by participants in the study. These assumptions were put aside by writing about them and acknowledging their potential to bias my interpretations. As a dietary supervisor, I have also witnessed the transitions that residents experience after moving to a nursing home, from their change in mealtime expectations to their adaptation to a new environment. My experiences have allowed me to see the fluctuating ability to be resilient over time. While acknowledging that being resilient is an ongoing process, this study has reinforced my prior experiences.

4.5.3.2 Validity and Reliability

The method of defining validity in quantitative research is much different than in qualitative research (Webster & Mertova, 2007). While quantitative research traditionally aims to establish validity by producing certainty in results, qualitative research aims to produce strong and meaningful data analysis that are deemed trustworthy from the original source (Polkinghorne, 1988). It is also considered valid qualitative research when it has been well grounded and supported by collected data (Webster & Mertova, 2007). Access, honesty, authenticity, and transferability are also various concepts used to define validity in qualitative research (Huberman, 1995). The expectation of producing accurate data cannot be applied to qualitative research because the “truth” or “reality” in which what has actually occurred cannot be claimed in research findings (Creswell, 2007). This is especially the case in narrative analysis,

where a small group of individuals' stories are retold. It should be clear that multiple interpretations in qualitative research can be valid and the decision on the validity of the results lies in the hands of readers (Webster & Mertova, 2007). I will promote validity by using the four concepts proposed by Huberman (1995).

Even though I cannot provide readers with access to the research data, I ensured my results were grounded with quotes from the collected data that captured the essence of the presented themes. Trustworthiness was also be ensured by demonstrating that there is “truth value” in the results, meaning that the multiple constructions are presented adequately and credibly with the original constructors (Guba & Lincoln, 1981). This was done by confirming my results with the original researchers involved in the Eating Together Study, and specifically the two interviewers for these dyads. The truthfulness of the results can also be presented by how plausible the reported results are (Webster & Mertova, 2007). In other words, the reported results may resonate with readers' experiences and even allow readers to gain new insight of an experience rather than presenting a “Hollywood effect” (Webster & Mertova, 2007). The level of trustworthiness achieved can also reflect the authenticity of the results. Authenticity can be achieved by convincing the readers that the results are presented in a serious manner, such as demonstrating coherence in narrating the story (Webster & Mertova, 2007); I believe I have attained these ideals. Lastly, I ensured transferability by providing a strong foundation and rich details to my stories such that readers can see the themes and consider them in various related settings (Webster & Mertova, 2007).

The method of defining reliability in quantitative research is also different than in qualitative research (Webster & Mertova, 2007). While quantitative research traditionally aims to establish reliability by producing consistent measurements, qualitative research strives for

dependable data (Polkinghorne, 1988). The dependability of data cannot be generalized across samples, but relies on individual participants (Creswell, 2007). The higher the trustworthiness the notes and transcripts are, the higher the reliability of the data set. The Eating Together study team enhanced the reliability of the data by checking transcripts against digital recordings. A team analysis approach was also used to enhance rigour. In addition, the main results were discussed with participants to ensure that they provided a general reflection of their mealtime experiences (Keller et al., 2010).

With valid and reliable data, this study aimed to contribute to the understanding of mealtimes for families with dementia by using thematic narrative analysis to analyze stories of changes that occur overtime. Rigour is just as important in qualitative research as in quantitative methods. The key is to be self-conscious during every step of the research process. As we critically examine every step, we can reduce the chance of distorting our thoughts and interpretations. Despite the subjectivity of interpreting qualitative data, I, as a narrative researcher, re-constructed plausible and coherent stories that reflected the mealtime experiences of families with dementia. In addition, I established a level of trustworthiness in the data to promote validity in my stories, but this does not mean I can claim my stories are the “truth”. Lastly, the reliability of the data has been achieved by the Eating Together study researchers to maximize the accuracy of the data. As a secondary data researcher, I had the responsibility of accurately utilizing the available data to narrate stories that are trustworthy and dependable.

Chapter 5: Results

The stories of two dyads featured in this thesis are reconstructed narratives demonstrating varying levels of resilience during mealtimes as dementia progresses. Both dyads present a different form of relationship. The first dyad, re-named Beth and Jeremy, offers a perspective on a spousal relationship whereas the second dyad, re-named Catherine and Loretta, offers a perspective on a mother-daughter relationship. A recipe of Loretta's journey with baking chocolate meringue pie offers a step-by-step guide to her life occurrence that was associated with the pie to demonstrate not only the importance of food for nurturing self and family identity and building connections, but also is a representation of this dyad's mealtime resilience. This recipe is being used as a creative element to narrate the story of this dyad. Rather than a long story, a recipe gives a step by step representation of the journey, using a specific mealtime activity to demonstrate resilience for a dyad over time. Both dyads' ebb and flow of resiliency can be witnessed longitudinally, with various factors coming into play, including the progression of dementia and environmental factors.

Various fonts were used to differentiate voices that narrate the story. Particularly in Catherine and Loretta's story, Catherine, Loretta, and the narrator took part in constructing the story, therefore, each of these voices is represented by a different font. Some quotes were used directly from transcripts. Furthermore, at the end of each segment of the stories my interpretive commentary is also in a different font.

5.1 Beth and Jeremy

5.1.1 Introduction

My name is Beth. I'm here to tell you about the mealtime memories that I'd shared with my husband, Jeremy. We've been together for 15 years, and "he did change me. He had a terrific influence on my life. Read on, and you will understand why I always told him, "There will never be anybody after you"...

5.1.2 Our Relationship

I remember a couple years back, I told our family doctor, "I don't honestly see Jeremy ending up in a home or getting that bad that he's out of control". I must have had my head buried in the sand, because things turned out differently than I anticipated...

Before I met Jeremy, I was stuck in abusive marriages, from a physically abusive one to an emotionally abusive one. After over ten years of torment, I just had to either live with it or get out, you know. I wasn't being treated the way I deserved to be treated. I wasn't being accepted the way that I am. Even growing up, my father expected perfection from me. There was no way I could always be perfect and the way others wanted me to be. Then all of this stress was lifted off of me when Jeremy entered my life and told me, "just be yourself, don't ever change". For once, I felt accepted. He was the first man to ever say that to me in my life. He was like a prince who swept me off my feet, and out of my misery.

Even princes, however, go through emotional turmoil. Jeremy was also in a previous marriage that came to an end when his spouse passed away. It was quite a shock to him. To cope, he drank himself silly trying to forget and fill in the gap. I guess you can say I was also his saviour who swept him off his feet. He would tell me, "the love and the care I get from [you

makes] all the difference in the world. I was alone and I couldn't care less. I met [you] and the whole world opened up." He no longer needed the alcohol. I filled in the gaps for him. Life was like a fairytale after we met. We brought each other back up from the lowest points of our lives.

There was no better word than to describe us as soul mates. We were always on the same wavelength. We had the same interests in just about everything, and we agreed on just about everything too. We had the same moral values, you name it. We were so much alike in that regard sometimes it's scary. And that was one of the reasons we got along so well, because there was not much to argue about, you know. Except sometimes we took the other side just to keep it going. But it's all in jest, and it's all in fun. So life was pretty good for us. As Jeremy would say, "she's happy when I'm happy and I'm happy when she's happy". And he was absolutely right. When we have that kind of relationship, it's hard to let go. In fact, we were always together, often times just the two of us. Even when I was in the kitchen cooking up a meal and he was outside building something, we would use our intercoms to carry on our conversation. We never ran out of things to say, there was always something going on between us, whether it was about planning our next getaway or something going on with our kids. Even when Jeremy needed to make a pit stop early in the morning and saw that I was still asleep and it was too early to be alone, he would go back to bed until I woke up to have oatmeal and coffee with him. We were pretty much inseparable! As cliché as it sounds, we didn't care what we did or where we went as long as we were together. That was the bottom line.

Dementia is an unpredictable syndrome. Some cognitive and behavioural symptoms are commonly presented among persons living with dementia, but how they are presented in action and words are unique among individuals. No matter how well

Beth understood Jeremy, what she had predicted his future to be was not how reality unfolded.

This section of the story provides a description of how they interacted as a couple. Clandinin and Connelly's first dimension of 3D narrative inquiry space looks into the personal and social interaction of the characters in the story. This dimension looks into the personal interaction by inwardly identifying internal conditions, such as feelings, hopes, and desires. It also looks into the social interaction by outwardly identifying the existential conditions, such as in people's experiences and events. Based on this dimension, this story looks inward into Beth's feelings and reaction to Jeremy's unexpected fate, leaving readers wondering, what happened to Jeremy? If the reality was unexpected, was Beth prepared to be resilient toward what would unfold? Beth initially had a hopeful expectation of Jeremy's fate, but when it was not what she had anticipated, there is a sense of disappointment in her voice. It also looks inward into the emotional attachment that the couple had; their strong connection established over 15 years translates directly outward through their inseparable physical space. This couple rescued each other from their past miseries. The mutual support gave them the capacity to look on the brighter side of their lives and place their negative pasts aside.

Clandinin and Connelly's second dimension of 3D narrative inquiry space attends to the order of place, things, and events. Based on this dimension, the story temporally starts from the present then moves to the past. This technique is used to show that Beth has lived the experience and is in the process of retelling the story.

Both characters took on a heroic role and rescued each other from their prior lives. The 'rescue' is a typical occurrence that distinguishes fairytales, further

demonstrated by the title 'prince' being granted to Jeremy by Beth. The reciprocal effort that Beth put forth to rescue Jeremy demonstrates the equal level of care this couple had for each other. I narrated their account of true love by displaying their inseparable connection through close physical space and continuous communication activities. Providing this background generates anticipation and curiosity among readers: will these soul mates be as resilient later on as they were at the beginning of their relationship? How will mealtimes change as Jeremy's Alzheimer's disease progresses? Will Beth's unconditional care for Jeremy be strong enough to maintain resilience throughout the journey?

5.1.3 His Diagnosis

One thing that I discovered when we first met was that there was something wrong with his memory. He was forgetting things, like I would say something to him and what we had done maybe in our first year of our relationship, or the first year of our marriage, or something. And he wouldn't remember. But he would remember way back when. He had no problems with the details of his early life or his first marriage or his kids, and any of that stuff. And soon after, he was diagnosed with Alzheimer's. Luckily, nine years down the road, the Alzheimer's hardly progressed. His outgoing personality and minimal signs could easily fool others that this syndrome was non-existent in him. Only I was able to see it. Anybody that knew him, like in the neighbourhood, they had a hard time believing that he had Alzheimer's. But *I* knew it because he forgot simple little things in the house. Or he'd ask me about something today and then tomorrow he'd forget about it. Or two days from now he'd forget about it. But I guess that's just

part of the disease. I said to him that he doesn't need to have a memory. I'll be his memory for the both of us.

Fortunately, I did not have to be much of a memory for him at that point. In fact, the diagnosis was not a factor that affected our relationship. We acknowledged its presence, but it was not always on our minds. The impact was not nearly big enough to hinder us from doing our daily routines. It was not a big deal to me since he was still my husband regardless of his memory, though I could sometimes sense his frustration for not being able to recall certain things. He thought of himself as a "freak" since he witnessed the rest of his friends in the Alzheimer's group regressing, I knew it was scary for him to witness his potential future. However, he would humour himself by saying "the guy upstairs" wasn't ready for him yet. I really do commend those moments when he would say, "Well, it's a real crutch for me. If I get into trouble I just blame it on my Alzheimer's!"

The resilience of Beth and Jeremy toward the Alzheimer's diagnosis was shown in this section of the story. Beth utilized strategies and acceptance to face the diagnosis while Jeremy used humour to lighten up the severity of the condition. By looking inwardly into both characters, their personalities can be clearly pinpointed. Beth can be seen as an observant and caring individual who could easily spot Jeremy's responses to his condition inwardly as frustration and outwardly as humour. It is unknown if Jeremy used humour as a defence mechanism, but he seemed to have accepted and sought the silver lining in his situation. Beth, on the other hand, did not show any sort of frustration at this point. Could it be because Jeremy's condition hardly progressed for nine years and she believed dementia would continue to be the invisible backdrop in

their lives? The situation, which is the third dimension of the 3D narrative inquiry space, is presented to exemplify Jeremy's forgetfulness in various events. The situation of being at home versus in his support group contrasts their resilience in these situations and how some of this resilience is based on their relationship and being the part of the other (e.g. memory) which is lacking. It is important to note that these changes experienced during the early years post diagnosis were minimal. How resilient they were as the condition progressed still remains a mystery at this point. However, the tone of the narrative suggests that things are about to change for the worse, building anticipation in this fairy tale.

5.1.4 Dining Out

With Alzheimer's seemingly out of our way, we enjoyed spending our retired life together going on excursions to satisfy our adventurous side. Short three-night trips were what we preferred to soak up the scenery without getting homesick. Adventures didn't just stop there, because going out to eat served as another vehicle to explore life. Cause that's why we liked to go to different restaurants that we've never been to before, to compare it to others, to restaurants that we've really liked and find different kinds of foods that we haven't had before, and things like that. We liked to experiment. Visiting various restaurants was like a game in itself where we would rate them and consider if it would be worth a revisit in the future. If we rated a restaurant as 'the best' and knew the cook was really good, we would be willing to make a long drive back just to relive that experience. Enjoying life was our focus and eating out was a big part of our enjoyment. Even when we were still working, we would go to great lengths just to get good food.

On one occasion, I remember he said to me, “we’ve got to be the only two idiots in the country that are walking through a snow storm to go and have breakfast!”

What we decided to eat and when we ate were quite spontaneous. If I was sitting down to do a bunch of paperwork then we would decide early that we were going to go for supper around 5:30 or 6pm. Which would give me lots of time to do some paperwork. And also gave me something to look forward to, as well as him, ‘cause he liked to look forward to it too. Even though eating was not always our top priority, we would always make time for us to sit together and dine, just the two of us. We enjoyed the spontaneity and did not eat by the clock. For example, “we might go out for breakfast because we [had] to go down to the city. And on the way back, if we had been horsing around the city and shopping and then we were tired, then we would go and have supper before we went home.” So I was *totally* spoiled that way. Jeremy acknowledged that cooking for two might not always be easy and would take me to eat out at times to take a big chore off me. Though I am sure he also just did not want to do the dishes! He was a sweetheart and tried to do everything to please me. He knew about my abusive past and would try to make up for it by courting me and wooing me during mealtimes outside of our home. Eating out was a rather romantic time for us to enjoy each other’s company and have a meal, a nice meal. It was a time we could spend one-on-one but not in the kitchen, because he knew I would need a break from that.

This focused time was important to us because we found that we discussed things that we would not normally have time for, or take time, or whatever, when you’re in a relaxed frame of mind, And it was just easier to communicate. We also had more meaningful conversations during this time. Jeremy realized that too, because he used to always say to me, especially in a restaurant, “I’m glad we’ve had this conversation”. Sitting across from each other while waiting

for our meals to arrive was a guaranteed time to communicate. On the other hand, it was not guaranteed at home because we also enjoyed watching the news during suppertime.

Communication wasn't confined to us alone, but when we ate out it could become a social affair when we went to restaurants with familiar and friendly staff. As much as I loved to spend time alone with Jeremy, we also loved to connect with others during mealtimes. Even during Valentine's Day one year, instead of being the traditional couple of eating out alone, we invited our next-door neighbour out for supper. The more the merrier, right? We knew she would spend Valentine's Day alone considering her husband was living in a nursing home, so what better way to provide her with companionship than through a nice supper?

This section continues to display the couple's ability to be resilient, despite the Alzheimer's disease diagnosis. In other words, they were able to come to terms with the diagnosis and enjoy life with positivity and appreciate the important things in life. The adventurous side of this couple, which was also reflected in other aspects of their lives, was brought out through their eating out experiences. It provides readers with insight into the couple's values -- that food was more than satisfying a physical hunger. They valued the enjoyment of the experience, the experimental aspect of trying new foods, and the entertainment of being in different situations and meeting new people -- they treated dining out as a game. These values were reflected in other activities such as their excursions. Different situations and events, whether or not they linked to mealtimes, revealed their adventurous life as a couple. They also enjoyed the experimental and entertaining side of visiting new places and deciding if they are worth visiting again. This dining out experience that this couple shared further confirmed their

inseparable ways of living together and building their connection. Treating dining out as a game could be a temporary escape from the day-to-day life of living with Alzheimer's and a chance to step out of their usual roles. Recalling specific situations in the retelling, shows that Beth held on to the simple pleasures that they shared and treasured these moments in her memory.

Jeremy used dining out as a vehicle to display his appreciation and care for Beth. It was an obligation he was willing to satisfy to compensate for Beth's past. It was another way for the prince to rescue the princess from the labour of cooking because she deserved to be spoiled instead. Considering that this is a story narrated by Beth, the internal feelings of Jeremy wanting to please her was open and known to Beth, showing that their relationship was based on sincerity, honesty and open communication.

Another important activity that this couple shared while eating out was communication activities. This guaranteed time to communicate allowed for an extension of knowledge they shared with each other. When Jeremy said, "I'm glad we've had this conversation" to Beth, it was an indication that they had either shared new knowledge with each other or they were able to work through a discussion that was left tentative in the past. This enriched their mealtime experience even more than merely satisfying their physiological needs, but also their emotional and psychological needs. Dining out was an activity shared between this couple that built their resilience, but they were not exclusive and used these opportunities to socially interact and appreciate others, whom they could share their resilience with. Their similarity in values and compatibility as a couple validates their relationship of being soul mates.

5.1.5 Dining In

Connecting with others during meals wasn't limited to being in restaurants; we continued to entertain, despite the dementia, in the comfort of our own little home. Living in a small, close-knitted neighbourhood, we, especially Jeremy, loved inviting our neighbours over. He just loved to have company, he loved to entertain. Whether it be a cup of coffee or a meal or whatever, you know, the camaraderie. Jeremy had an open door policy, especially in the evening. He turned our porch light on at 7:30pm and the neighbourhood knew our coffee pot was on. And it told them that they were welcome to come and have a coffee. And sometimes they did and sometimes they didn't. But most of the time we did have company. And that was the kind of neighbourhood we lived in as well. People were very friendly. And we just loved it there. Jeremy always had a welcoming gesture to bring the community together. He would warmly say, "Do you want a cup of coffee? Come on over!" While Jeremy used coffee to bring the community together, I would occasionally invent new desserts and other dishes and invite the neighbours over to try them out. I loved to plan and prepare food for others because I like to fuss. It is a characteristic I got from my mother.

I fussed more in the kitchen and eating in with Jeremy ever since I was diagnosed with diabetes and knew I had to watch my diet. We used to eat out 6-7 times a week, but had to limit that to 2-3 times a week after my diagnosis. Jeremy knew I was always conscious of our health and wanted the best for the both of us. He used to say, "She likes to study medicine, that kind of thing. That's why she's so into diet and symptoms like that. I don't think she's a health freak but she's very conscious of what we do, and why. There's nothing wrong with that. And I'm sure that we both benefit an awful lot by it. So in that respect I don't have to worry about it too much because I'd forget anyway." No I wasn't a health freak, but I knew what a balanced meal was.

And Jeremy knew he could rely on me to provide a pleasurable and healthy meal every time we ate in. I was not a good cook when I first met Jeremy, but it was his encouragement and his willingness to be my taste tester that got me to experiment with food. I would say to him, “What would you think about this. Try it. You don’t know till you try it!” and he would gladly respond, “I love that, something different”. That’s why I really enjoyed making meals for him because I knew he was going to enjoy eating it. I could feed him *anything* because he would try anything, he would eat anything. Very, very seldom did he ever say he didn’t like something. With his encouragement, I always had meals on my mind, like what I should make for the next meal or how to spice things up. I just didn’t want our meals to get boring, but rather I wanted every meal with Jeremy to be enjoyable. He did recognize my efforts and appreciated my cooking. He thought I was an excellent chef because I liked taking a recipe and altering it and making it better. I wouldn’t consider myself as a chef, but I really enjoyed surprising Jeremy with new dishes that we had never tried before or I had never made before, because it was always an enjoyable experience, and he loved that.

Just as a general rule, Jeremy decided he would be our dishwasher, just to lighten up my load a little bit, but otherwise he would usually stay out of the kitchen. However, rules are meant to be broken, and he would be glad to help around in the kitchen if I needed it. If I asked him he would come out and peel the potatoes or peel the carrots. He would do anything I asked him. But I very seldom ever did. But if we were having a big party and I wanted to make a potato salad or whatever, yah, he would definitely come out and help me if I asked him to. Cut the onions so I didn’t cry. He was definitely a sweetheart and it was worth all my time and effort to cook up meals that matched his preference. I would often ask him, “What do you feel like?” and I often got responses like, “I don’t care. Whatever you want” or “I don’t have any preferences”, but I

still tried to involve him in the decision making process every time in case he had a sudden craving. We also decided together where we would eat in the house, whether it was in the living room where we could watch the news with the TV tray or sit near the window where he could watch the birds. It didn't matter to me as long as we were eating together.

Utilizing coffee as an invitation, Jeremy established connections with his neighbours and helped bring the community together. Turning on his porch light symbolized his warm welcoming gesture to establish connections with anyone in the neighbourhood. It was also an identity he created for himself that was well known and accepted among their neighbours. Situated in their little home, Beth and Jeremy's social interaction with their friends and neighbours unfolded. Jeremy created an open environment using food as a point of connection, and his Alzheimer's didn't seem to exist to others. Beth and Jeremy lived life fully and normally at this particular time and place. Will their social interaction with others change as dementia become more prominent in their lives?

While Jeremy would take Beth to eat out as a way of showing appreciation and care, Beth cooked for Jeremy as a reciprocal way of showing gratitude and nurturance. The mutual support was evident where Jeremy would take Beth out to woo and court her, and on the other hand, Beth experimented with her cooking and would ask Jeremy for his opinion and preferences to make sure he enjoyed the food. In this way they nourished each other, allowing them to be resilient as the dementia progressed. Will the mutual care be reciprocal as they move forward in their lives? It became Beth's objective to fulfill his satisfaction, supplemented by Jeremy's continual encouragement

to experiment and grow in her expertise with food. It was a cycle they had established to consider the needs of the other which in turn satisfied their own emotional happiness, and mealtimes was involved in this fulfilment process. This was a personal desire that they both acquired due to their unconditional love and care for one another. This personal desire provided them with the inner strength to move on without letting Alzheimer's become a barrier.

5.1.6 The Double Identity

Life with my prince was smooth sailing until Alzheimer's progressed and decided to take him over. Living with a person with essentially two identities was almost like walking on egg shells with spiked heels on. One with Alzheimer's and the other was my regular sweetie. Jeremy was the gentlest person, but a slight trigger could unleash the other side of him-- if I said the wrong things or used the wrong expression he would give me the silent treatment and be mad for days. At times the Alzheimer's side would completely take over and he would say the most hurtful words, like "our marriage is falling apart, we're falling apart, I think we'd be better off separate". During those moments, I just had to walk away and avoid discussing it with him, because it just wasn't going to happen! Even so, I still respected him and treated him as if he didn't have Alzheimer's. When he got caught up in his rage, I just calmly listened and when the rage died down, I would tell him, "I'm sorry honey, you know, I'll try harder" just to satisfy him and go on with our lives. As much as it bothered me, I had to keep reminding myself, "Hey dumb, dumb, that's not [Jeremy], that's not him yapping. That's his, you know". As a deeply religious person, I always turned to the Lord when I needed strength to deal with Jeremy. I would also turn to books, which were an escape from reality. He would sometimes get frustrated

with himself for his memory decline, but I kept telling him, “it’s the cards you were dealt” and he eventually understood that. His ability to be our household dishwasher was also declining, because he wouldn’t remember where the dishes went and would just leave them on the kitchen counter. It wasn’t a big deal for me. I never confronted Jeremy about it and just put them back where they belonged. There was no need to because I knew it wasn’t his fault. Day by day, his condition worsened, but his desire to eat out never died down. He was getting weaker and weaker and weaker...he didn’t really complain until it got so bad that he couldn’t lift his head off the pillow. I sometimes wonder now, did he want to go out all the time because it was easier for him to walk to the car and walk to a restaurant than do the dishes, because he always helped me with the dishes? Not knowing what was happening to him at that point, he wanted to eat out almost every day.

The progression of Jeremy’s Alzheimer’s was an indication that a turning point or a major event was approaching. This is the point where Beth remained resilient by developing strategies as unexpected changes continued to challenge her. She resisted interacting with the Alzheimer’s identity and only with the “regular sweetie” that she knew. The way that this section was storied provides a progression of how Beth became gradually resilient to the hurtful situations she encountered with the Alzheimer’s side of Jeremy. She went from feeling hurt to ignoring hurtful words to coming to terms with the situation and even convincing Jeremy to have a more realistic mindset. She persisted in not only preventing from “breaking egg shells with her spiked heels”, but also to bring peace into her emotional wellbeing. However, it was evident that she would put Jeremy’s dignity above her own needs, showing her unconditional care for her

husband. Veiling the progression of his forgetfulness and her emotional pain of dealing with the changes were examples of how Beth protected Jeremy's dignity in an attempt to preserve the status quo. She created a manageable environment for Jeremy to leave the Alzheimer's identity caged in. Taking Jeremy to dine out every day showed Beth's persistence to satisfy his every wish and conceal his declining abilities while supporting his 'prince' identity; a way of continuing the fairytale where the prince continued to rescue her from the drudgery of kitchen duties.

5.1.7 The Turning Point: Surgery

Finally he was admitted to the hospital and the doctor found cancer in his throat and he had to undergo surgery. If I knew how much he had to suffer from that surgery, I would never ever have agreed for him to go through with it. That surgery absolutely destroyed him! He had to be put on Risperidone, an antipsychotic drug for his violent behaviour after the surgery. However, when he was transferred to a nursing home, things took a turn for the worst. When he went in the hospital, he was on 0.75 milligrams of Risperidone. When he arrived [to the nursing home], he was on 7.5...because somebody made a mistake, in the hospital. It's a wonder they didn't kill him. Even the doctor shuddered and said, "Oh God, the most we prescribe is 5 milligrams, not 7.5!" Even though the doctor slowly reduced his dose, he never really perked back up again.

His life at the nursing home did not make his situation any better. In fact, he absolutely hated living there, and I hated seeing him there. He would have the nurses call me and he would say, "When are you gonna come and get me?" or "I want to go home". He would ask me over and over when I visited because his memory recall was gone at that point. Every time he asked

me, it tore me up inside because I couldn't fulfill his wishes. I couldn't save him from that unholy place. One of my girlfriends told me that "if you've ever dealt with an Alzheimer's patient, you don't - you *don't* tell them anything that's gonna upset them". At the same time, Jeremy and I established the rule from the very beginning to base our relationship on total honesty and tranquility. How could I now dare to break that rule that I had pledged to uphold? So I tried to be as truthful and as gentle as I could. I would say to him, "I can't right now honey, but I promise I'll be up there as soon as I can tomorrow".

That horrendous place reeked of death. The way that nurses treated residents was totally inhumane. They didn't have an ounce of professionalism in them. How could they call themselves health professionals when they don't give a fiddlers' fig about their patients nor treat them with respect? From the moment he was admitted there, his health deteriorated. The nurses had no patience to provide encouragement for Jeremy to eat. He had lost over thirty pounds. I ran my hand down his back, you could count the vertebrae in his spine through his t-shirt, and, and this space in between the collarbone and the shoulder bone, you could, it was so deep, from his loss of weight. In fact, they would just wait for me to visit so I could do their job and encourage Jeremy to eat his food and take his pills! Of course I took over, but some nurses just couldn't figure out that he would refuse to cooperate with them because he wasn't being treated with respect.

When he was first admitted, he refused to eat in the dining room, he just wouldn't go. The nurses never bothered to figure out the reason or provide any encouragement. Again I stepped in and found out that he wouldn't go because he thought he had to pay and he didn't have any money. So I formulated a creative strategy and told the nurse, "Ok I'm gonna put \$5 in his drawer, like a five dollar bill, and you guys can just tell him, well I've got the money here for

you, so you come with me”. This strategy worked, but hells bells, even I wouldn’t want to dine there! I swear I would never enter that dining room, I would not. Three hours before mealtime, I witnessed residents in their wheelchairs waiting in line down the hall like they were herding cattle. It was a grim scene, but it was the only thing in their life they had to look forward to. Jeremy didn’t like to eat in the dining room. Choking fits, coughing fits, and staff jamming the food down residents’ throats turned him right off and made him sick to his stomach. The three women he sat with at the table were just yammering away and excluded Jeremy in their conversations.

After several times dining there, he refused to eat there again. I ate with him several times in a special room, but the experience was likely tougher on me than on Jeremy. Not only was the food bland, but the conversations we used to have during mealtimes were not happening anymore. I’d lost that partner who I’d always made plans and decisions with. Since he didn’t want to eat in the dining room, I made sure he no longer needed to step foot into it. Eventually he ate his meals on his bed. It bothered me a lot just to watch him eat. He would take a spoonful of his ice cream and his hand had a tremor in it, and it’s, and you sit there and wonder, is he going to make it? And it’s just so sad to see Jeremy so, so weak. Everything he did had to be so slow and deliberate you know. And I tried very hard not to help him too much, because I knew he didn’t want me to...It was very difficult to watch him do something that was so simple with supreme effort, but I let him do it himself just to preserve his dignity.

Considering the nursing home was very far from our home, I couldn’t always be there for Jeremy and was forced to rely on the nursing staff to make sure he was eating. However, I found out one day that meals were not brought up to him and a nurse manager had the audacity to holler out, “well, Jeremy didn’t eat his supper again!” How *DARE* she say it with such pride! I

had to complain to her and made sure Jeremy got all his meals! How could they expect him to get down those bloody steps or in that elevator on his own! Those negligent nurses also tried to put Jeremy on a modified diet when he didn't need to be! They had mistaken his choking on the mucous in his throat as choking on his food! The bland food at the nursing home was already tough to keep down, I would not allow Jeremy to eat "mush" if he didn't need to! After much advocating, they finally listened and allowed him to continue eating regular foods. I couldn't help but feel sorry for Jeremy for all the torment. To take this torment away for a few hours and help him relive his desired moments, I tried taking him out to a restaurant that he enjoyed when he was still able. As weak as he was, he found the strength to finish his entire meal plus desserts. It was a temporary rescue, but it was the best I could do.

The only person who had the ability to truly rescue him was God. I prayed every night that God would take him home. As painful as it was for me, I had comfort knowing that after eight months of torture, he was finally in God's arms.

This section of the story reveals how Beth completely took over the heroic role and rescued Jeremy again and again to fight for his dignity and quality of life. She briefly narrated from the present her feelings of guilt and regret for allowing Jeremy to follow through with the surgery, but transitioning back to the past showed that she was able to be there for Jeremy as negative events happened one after another. She stepped in to save him every time a problem arose. Her focus was so entirely on saving him that she disregarded the bad feelings the nurses might have felt against her because it was not her concern. Her only concern was Jeremy's well being. She channelled her inner thoughts directly and outwardly toward whoever prevented Jeremy from having the

enjoyable mealtimes he deserved, showing her unconditional love and care that she sustained from the start. The saying “I’m happy when you’re happy” stayed true throughout their story, as she felt his frustration and struggle for dignity. When Jeremy was unhappy living at the nursing home, it tore her up inside. When Jeremy was being treated with disrespect, she was filled with rage. Initially portrayed as a timid individual, her fiery side was automatically unleashed to effectively advocate for the love of her life. Her anger was clearly shown, but the guilt and regret lingered deep down. It was not a situation she had prepared herself for, but Beth persistently dealt with the social and environmental conditions at the nursing home. Using her inner strength, the possibilities of fighting for her husband were apparent.

She preserved Jeremy’s dignity by treating him as if he didn’t have Alzheimer’s. She treated him like a normal human being even after Jeremy’s condition had progressed to this advanced stage. White lies would have easily satisfied Jeremy considering his lack of memory, but Beth vowed to stay truthful to her husband, no matter what state he was in. Beth maintained compassionate connection with Jeremy, even if it only was sustained for as long as Jeremy could remember. Ensuring Jeremy received regular textured meals when she believed he had the capability to eat them was another way Beth treated him like a normal human being and recognized his remaining abilities. Taking Jeremy to a familiar and comforting restaurant was Beth’s way of balancing the daily stresses they both faced and holding on to parts of the past experiences they both shared and enjoyed.

Beth knew her abilities were limited and turned to her faith for assistance. It was not until Jeremy fell into God’s arms that Beth finally shifted the focus onto herself and

sought comfort from her faith. With that comfort, she no longer had to consider Jeremy over herself and retired from her heroic role. The spiritual interaction she built with God restored her resilience and provided her with a sense of peace and closure.

5.1.8 Epilogue

As for me, ...well, after Jeremy died I lacked the motivation to get up in the morning. What was the point? I no longer had that close companion to go on with my day. This took awhile to overcome. Mealtime without Jeremy was hardly any better. From the time he was admitted to the hospital all the way 'till the year after he passed away, I lived on cereal and TV dinners. Eating was no longer an enjoyment. It was merely a necessity. And instead of my beloved Jeremy, the TV became my companion. It was not until a year after he passed that I started cooking again.

Now, my girlfriends are my main source of support. Whenever I'm with them, my problems and worries are put aside for awhile. The four of us have lunch every Sunday after church and dinner before we head home. I enjoy their company. Even though I'm alone, I don't consider myself to be lonely, because I have made Jeremy my guardian Angel. I will stick to his words to stay positive. He used to say, "As long as you have positive thoughts you'll have positive results. If you have concerns and doubts that's when you start to have problems. So I think you can control your own destiny."

Until I can be with Jeremy again, in the meantime, I am reaching out to my daughter, Stephanie. Stephanie lives in Brookville and while we've been estranged for many years, I am driving to Brookville to have dinner with her in a restaurant every few weeks. In fact, recently, I was having dinner with Stephanie in an Italian restaurant, and I looked up and my eyes met those

of one of the researchers from this study. We looked at each other for a long moment. While Stephanie, whose back was facing the researcher's direction, chattered on about her problems, the researcher and I smiled gently at each other, nodded, and, well, we both returned to our families and our lives.

I still have my occasional sudden meltdowns, but I'm dealing with it. I know one day I will join Jeremy. When that time comes, I want my ashes put in the urn with his and they're to be spread together-- in the end, we will be spending every moment together, happily ever after.

As a concluding part of the story, Beth's brief story as a widowed individual was narrated as an epilogue. It was not part of the main story because Beth's focus had always been on Jeremy, rather than on herself. Still, her level of resilience and how to sustain herself was clearly shown in this segment. Finding time to reach out to family and friends was a focus she made for herself for moral support. She extended her social interaction to rediscover herself and increase awareness for the silver lining as a widowed individual. Her memories of Jeremy's words were a spiritual interaction she held onto to maintain positivity. Being together was a main factor in this couple's relationship, and this idea remained even after Jeremy passed away by making Jeremy her guardian Angel, holding on to his words, and wishing to have her ashes spread with his ashes.

The situation of meeting the eyes of a researcher cleverly demonstrates that despite what had gone on in the past, life goes on. What was once discussed in the research interview remained in Beth's past, but her life does not end there. A glimpse of Beth's present showed that she continued to use mealtimes as a way to connect with

others, including her daughter that she used to have a tough time getting along with. Beth sustained resilience and anticipated with hope that she will be reunited with Jeremy. Mealtimes continue to provide a venue through which healing takes place and connections are sustained, while resilience is developed.

5.2 Catherine and Loretta

5.2.1 Introduction

On a beautiful Saturday afternoon, Catherine leaves a cafe juggling two iced cappuccinos and a sandwich as she walks back to her car. “Here you go, Mom” said Catherine as she passes an iced cappuccino and half a sandwich to Loretta. It is Catherine’s day off and she decides to take Loretta out to enjoy the weather so she can take a break from facing the four walls of her room at the Lakeview retirement home. A main factor for making eating out an adventure is not necessarily the food, but also the surroundings. They gaze out the window toward the beautiful cemetery, watching the trees and grass sway with the light breeze. With Loretta’s dementia progressing, Catherine knows she will find satisfaction in remembering the past, and proceeds to start their story by reminiscing about her diagnosis. This is a conversation between Catherine and Loretta as they enjoy the bright summer day.

5.2.2 The Diagnosis

“Mom, remember the day I said to you, ‘You know what Mom, you seem to be having a little bit more difficulty with your memory, and I think you should go to the doctor and get that checked out’ .”

“Yes I remember, what gave it away?”

“For ten to eleven months, I gradually noticed signs that you were getting more forgetful, and I struggled to understand what that meant. So I called Carol, remember her?”

“Was she the nice young lady you brought to have dinner with me at Lakeview?”

“That’s her! She works as a nurse practitioner so I consulted her about your memory difficulty. She suggested that it was time to pay the doctor a visit. That evening when you misplaced your quilting needle, it was a perfect time to suggest that we should see Dr. Taylor.”

“I saw how concerned you were and didn’t hesitate to take your advice. I’m sure glad I did because Dr. Taylor diagnosed me with a mixed dementia of Alzheimer’s disease and Vascular Dementia.”

“It all made sense. I can let a lot of stuff go, much more easily, because I know what I am dealing with. It has been very gradual and you still are quite independent. So there has been some dealing, but you are coping.”

“Going to church and my faith has been a huge support for me, but you know, nothing compares with the support you have given me unconditionally. I may be losing my memory, but I will never forget the times when you wanted

to come over to my house for dinner, because what means a lot to me will never slip my mind.”

The beginning of the story was situated in Catherine’s car that was parked near a cemetery. This has significant meaning to both participants because they regarded this moment as one of the most memorable mealtime experiences with each other. To Catherine, it was a break from her busy life while spending time with her mother. To Loretta, it was an opportunity to reconnect with her daughter and escape from her usual routine at the retirement home. The beautiful scenery enhanced their mealtime experience, making this time visually memorable. Taking time to incorporate simple pleasures in their lives together was this dyad’s way of being resilient. Catherine used reminiscing as a basis to converse with Loretta. This way, the conversation not only serves to connect with her mother, but also to protect her mother’s dignity and identity.

By reminiscing, Catherine and Loretta are going backward to retell their story. Unfolding events in the past reaffirmed their identity as a mother and a daughter and how they were as a dyad to that present moment. They discussed the diagnosis with calmness and openness indicating their acceptance toward Loretta’s condition despite the current and anticipated challenges. Loretta established social relationships with others at church and a spiritual connection with her faith helped her gain acceptance of her diagnosis. Loretta looked outward to compare the connection she has with Catherine to connections with others, demonstrating that the strength of the connection with Catherine was at a whole other level. The support from Catherine exceeded well beyond others and was a primary source of support to maintain her resiliency. She

showed her inward appreciation for Catherine by confidently claiming to remember everything that means a lot to her, despite her diagnosis.

5.2.3 Their Relationship

Loretta looks over and smiles as Catherine takes another bite out of her sandwich. Catherine was the only person who had visited in awhile and she wished the day would not end. She's enjoying this present moment because she enjoys all the times they share stories; there is always something to laugh about. In the midst of her thoughts, Catherine starts coughing. Loretta reaches out and pats her gently on the back.

"Are you alright, dear?"

"Oh yes mom, I'm alright. I choked just thinking about that time we were baking a chocolate meringue pie together and I caught you almost adding another tablespoon of cornstarch to the filling! The pie still turned out well though and everyone at our church loved it! Remember how wide little Charlie's eyes got?"

They both laugh. Reminiscing about the past was always a source of a lot of laughter. It was also a great trigger to jog her memory. However, this time, Loretta isn't sure she remembers this particular incident. As familiar as it sounds, it doesn't quite ring a bell. The thought of being a burden to Catherine starts to grow in her, and it reflects in her concerned expression, in which Catherine immediately picks up on.

"Mom, don't worry about it! It's a pleasure to bring you out and have lunch with you. It's also a privilege. It is nice to feel useful to somebody,

in such a way that is so easy, really. It is not difficult and it is not particularly time consuming. And it is also enjoyable. I don't have anyone else who relies on me to the same degree. So right now I get a lot of satisfaction out of being useful to somebody. The satisfaction comes from knowing that you are grateful for all I have done for you. You are just a lovely person, very appreciative. And you know, it just feels good. It might be a duty or an obligation, but to me it doesn't always seem that way because I still want to do what I ought to do. Although you are losing the ability to deal with complex and new situations, you still have the ability to appreciate me. I find it very rewarding to care for you, Mom."

Loretta can't quite find the words to express her thoughts as she's listens to Catherine express hers, but Catherine gives her a sense of emotional support and comfort just from her presence. Being together like this, translates into the feeling that, "Oh, I'm ok now that you're here". With Catherine's reassurance, Loretta smiles and takes a sip of the iced cappuccino, sending a cooling sensation smoothly down her throat.

Loretta appreciated Catherine's presence and showed this nonverbally through her smile. She valued every minute spent with her because her contact with other people was minimal. The connection was important to Loretta because of the emotional support that Catherine provides. Growing up as a family, they loved to reminisce. Doing so gave them a sense of continuity and appreciation for life. Having the ability to remember the past and connecting it to the present and their hopes for the future

reaffirmed her valued presence. As much as Loretta was dependent on Catherine's physical care and emotional support, Loretta held onto her role as a mother to care for her daughter, by not wanting to be a burden. Flowing with the necessary changes while trying to hold onto the roles and routines that do not require changing is another way to be resilient.

Catherine's resilience stems from her positivity as a care partner. Rather than seeing the added role as a burden, she sees it as a privilege to care for Loretta. It is as if Loretta has also done Catherine a favour so she could feel useful and needed. This idea led Loretta to shift from feeling a burden to being someone of value. Catherine's explanation caused Loretta's feelings to turn from worried to relieved, which was symbolized by the sip of iced cappuccino. Catherine also unwittingly looked back to recall a past experience which involved Loretta making a mistake; this was not meant to intentionally test Loretta's memory but to find a source of humour to exchange and reminisce about. Recognizing Loretta's dismay at not remembering the event, Catherine turned the situation around to be affirming for her mother. This again was Catherine's strategy to protect Loretta's dignity.

5.2.4 Eating Together

Ever since Loretta moved to Lakeview, she didn't have a chance to go back to the double level condo that she used to live alone in. With Loretta's agreement, Catherine starts her car and drives three blocks towards Stone Creek Lane. As Catherine turns into the street, memories of eating and cooking together slowly flood back.

“I remember one of the things I looked forward to was waiting for you to get off of work and eating dinner together on the round wooden table. Two to three times a week, it was an excuse for us to get together, share some company, and sort of break the monotony of my own company and add a little interest. It gave us time to socialize.”

“I can’ t imagine sitting together for meals and not exchanging any words at all! When we ate together at your house, we were able to face each other. It provided an opportunity to actually connect with another person. I mean just to slow down to be present and to talk with that other person. It doesn’ t mean that we don’ t have periods of companionable silence by any means, but it sets a framework for just removing other distractions and just being together. After a busy day of work, it was exactly what I needed.”

Catherine parks on the curb beside the condo and they look into the window where the dining table used to be, and reminisce about the days they ate on that table every time Catherine visited.

“I valued that time together with you because while sitting face to face, it allowed time for conversation that we might not otherwise have had if we were not eating together. I particularly enjoyed getting updated on your activities, because I felt like I was more like a part of your life, it gave me

something else to think about besides what was going on in my own little house.”

“You might not understand all the technical aspects of my explanations about my work, but it meant a lot to me to have you as a sounding board. It is good for me to be able to talk about it and very often you ask good questions, it helps me think about things differently. It is nice for me to have someone to reflect on my day with.”

“I may not understand everything, but I am always interested in your work life and enjoy the sharing aspect of having you confide in me about your personal life.”

“Often times you do understand, and it gives me a form of validation, even if you don’ t provide any sort of solution. It was so natural for us just to sit together and exchange ideas as we ate. Since we lived separately, coming over to eat dinner with you was an excellent opportunity for me to check in on you even though I used to call you frequently as well. Essentially it was a time to fill in the needs of spending time together, connecting with each other, providing mutual support, and having various discussions, all at the same time.”

“We certainly are productive while we eat! I know you like to keep yourself busy when you eat by yourself, working at your desk like you do. You’ve got to take care of yourself!”

“I know, Mom. I always see mealtimes as a time to multitask when I eat alone. I don’t like the feeling of sitting alone in silence and just eating. I still remember what grandma used to say, “you don’t trail your food around the house...it’s much easier to keep it clean if you don’t!” With my busy work schedule, I have no choice but to skip occasional meals or eat while at work. You know, it’s a different story when I eat with other people. When I’m with you or when I’m with other people, I never think that I should be reading a book at the same time, or you know. I think eating with another person takes you away from thinking about all the other things that you need to be doing.”

“That’s why I love when you would come to eat dinner with me. Not only was it an enjoyable activity that I looked forward to sharing with you, but it was also an opportunity for me to prepare you a good meal, with you as my sous chef cooking alongside with me. I know you don’t often eat well, so cooking a meal was an appreciative gesture and acknowledgement for your hard work.”

“Thanks, Mom. In return, I would put a kettle on for tea at the end of our meal.”

“Oh yes, I loved to be waited on. I also loved that we were often so spontaneous with what we decided to eat. You would call from work and together, we would bounce suggestions off of each other and plan around what was available in my fridge and what we wanted to eat. You were so trusting and diplomatic towards me and always asked for opinions before making decisions.”

Catherine smiled knowing she was being appreciated, but at the same time she was reminded about an incident that suggested otherwise. On a typical day she dropped by Loretta’s condo to eat dinner with her; Catherine had growing concerns over food safety in her mom’s kitchen. She remembered walking in and there was a package of hamburger meat on the counter. She reached out and felt it, just to see how cold it was. She never checked to see whether it ended up back in the fridge or back in the freezer. One of the things that she was starting to think of was if they were going to do something like cook meat, she would bring it. From then on she decided to buy fresh meats the day they shared a meal to avoid Loretta from dealing with raw meats when she cooked alone. The role of cooking meats was also given to Catherine while Loretta cooked the vegetables. Catherine decided not to bring this up and continued on with the conversation.

“Of course, Mom. I always consult you first. Like when I would open the fridge and do a quick scan and decide with you if we should throw out certain

foods that I thought had been left uneaten for too long. I always want to do things with you, not for you, like food preparation. It was a valuable time for us to connect. It didn't seem like food preparation was lost time, because if we are preparing food together...maybe at the same time we are compiling a shopping list, 'cause I could see what you were missing in the fridge and we would think about what we might want to have later in the week."

"I think compiling the shopping list was really helpful because it only served as a reminder of what I needed to buy, but also a reminder of what not to buy by compiling a list of items that were available at home. I'm glad you did it with me or else a lot of foods would be left sitting in the cupboards and not being used!"

Catherine often made the effort to do this activity with Loretta rather than just doing it for her, because the results were more rewarding. It took more energy and more time and more patience to do it the way she did, but maintaining this strategy also served to maintain Loretta's trust for Catherine; their relationship was more important than the quality of the shopping list.

"Even so, I know you would much rather enjoy grocery shopping on your own."

"That's true, because I really enjoy simply walking around the store without having to shop every minute and having to search for specific items. I

don't like treating a shopping trip like a chore. I see it as an outing where I can take my time keeping myself up to date on what is available and surrounding myself with food. It was an opportunity to leave the house and put the isolated feelings aside. Unfortunately..."

Before Loretta can finish her sentence, she watches a car of the same model and colour as her previously owned car drive by, and remembers that her freedom of driving to the grocery store was taken away when she was unable to renew her driver's license.

Looking forward to the simple pleasures of eating together was another way this dyad sought to stay positive. Looking forward to the sources of pleasurable times diminished the present pains of coping. With Loretta as a widowed mother and Catherine as a single individual, they shared a special companionship similar to two best friends. Utilizing mealtimes as a vehicle to bond, Catherine and Loretta found various positive meanings and events surrounding that round wooden table.

Catherine again was able to identify a useful role for Loretta as a "sounding board", even though she might not have a clear understanding of Catherine's explanation of her work. This provided Loretta with an acknowledgement that she had remaining capabilities despite her diagnosis. She was still acknowledged as a mother who was able to provide emotional support for her daughter. She was also the mother that was able to provide proper and nutritious meals for her daughter when they had that guaranteed time to have meals together.

The situation involving Catherine's concern over Loretta handling raw meats was narrated in her mind and was not part of the conversation. In spite of Catherine's outward projection of her feelings towards Catherine, she hid her concern this time to protect her dignity; this was what was most important at this time. It was Catherine's flexibility to balance maintaining honesty and protecting dignity that demonstrates their active work towards resilience as a dyad.

Catherine was displayed in the story as someone who often multi-tasked and was also motivated to get work done. Despite this nature, Catherine insisted on taking the long route of putting together a shopping list, keeping in mind the importance of including Loretta in the planning process. This was again Catherine being flexible to accommodate for her mother, recognizing that building Loretta up in this way would have greater positive effects in the long run.

5.2.5 Loss of Freedom and Independence

Driving was one of Loretta's favourite things to do and to have her license taken away was heartbreaking news, making her feel incapacitated.

"I know you are still upset about losing your license, but you were still able to take the taxi!"

"The level of freedom just wasn't the same, Catherine. I know it was my next best option though. I was still able to cope with the loss and used the taxi a few times to run errands."

Catherine suddenly remembers a situation where part of it remains a mystery to her. Loretta found the motivation and resources to take the taxi to the grocery store to buy some ingredients for a potluck party even after Catherine had already bought the ingredients with her the night before. She thought to herself, “She wouldn’ t tell me why she needed to go. Perhaps she dropped one of the bowls and ruined one of the salads we had made together the previous day. In the end, she bought stuff that she had originally had in mind to make in the first place, but I had insisted it was too complex to work on the day before. I don’ t know whether it was because she decided that she didn’ t have enough to do both of them or that she really wanted to make what she had originally planned...and so it is still a bit of a mystery to me, but she managed to do it...” If Loretta didn’t want to mention it, Catherine allowed the mystery to remain a mystery.

“And this scar on my arm, will always serve as a reminder that I can no longer cook alone. My privilege of cooking alone was taken away when I accidentally fell on the oven door and the stove flipped on top of me. Even Mrs. Dawson recommended for me not to use the stove alone and should resort to the microwave only.”

“I think that was just a freak accident, especially since you just had your hip replacement surgery. I think you’ ve got rights, and you have the right to be as independent as you are able to be, and no one should take that

away from you unless there' s evidence demonstrating that you are not safe.

And I guess those are my principles as well as what I would want for you, out of love.”

“I also think it was just a freak accident, but I didn't want you to worry and so I stopped cooking alone altogether. When I saw a flyer for a delivery meal service for seniors, I knew that was going to be my next option. I understand that I am no longer in the position of being the hostess. I used to like that. I suppose I'm sure other people who do, do a lot of entertaining would feel the same way. There is something about preparing and serving a meal to people that makes it different. Well, I like the feeling of being served too. I got used to that when I ate out with you.”

“Speaking of eating out, Daniel and his family will be coming to visit in two days, your grandchildren are requesting to eat Chinese buffet this time, what do you think?”

“Sure, I have no problem with that. Can you remind me to bring my debit card on that day?”

“Do you remember you PIN?”

“Um...”

“The formula is your birthday month and your favourite number.”

“Oh yes I remember now! I’m afraid you will have to remind me of this formula at the buffet again.”

“Not a problem, Mom. It’s getting dark, we should probably head back to Lakeview. It’s almost dinner time.”

In this section, Loretta didn’t show quite as much resilience since her driver’s license symbolized her freedom and independence, and both were taken away from her. There was a sense of struggle within Loretta yet she battled through her losses and settled for using the taxi when she wanted to go out on her own. Her resilience was demonstrated by Loretta’s mysterious shopping trip. She took initiative to utilize her next best option to be independent. In other words, she adapted to the new normal while holding on to what she found to be valuable. Why did she have to hide her reason to grocery shop from Catherine? Could she be trying to prove to Catherine and herself that she was still capable of going grocery shopping and cooking for a potluck party all on her own?

It seemed that part of being able to overcome the loss of independence was for the sake of Catherine. From the beginning of the story, it was evident that Loretta did not want to be a burden to her daughter. Even with Catherine’s permission to cook alone, Loretta made her own decision not to cook so Catherine wouldn’t have to worry. Out of love for her daughter, Loretta gained capacity to be resilient and gave up her passion for cooking to preserve Catherine’s emotional well being. She once again took

the initiative to look for the next best option namely, a delivery meal service. Similarly, Catherine found the capacity to let go and not over-manage her mother's life. In other words, she provided the space for Loretta to take risks in order to preserve her independence. Out of love for her mother, Catherine loosened her protective role unless it was deemed necessary, regardless of how worried she might have gotten. This was a form of personal growth to learn how to be a care partner balancing caring for someone while providing enough space for the person being cared for. Personal growth is essentially developed as life experiences accumulated overtime and demonstrate resilience.

5.2.6 Transition to the Retirement Home

The sun is beginning to set, Loretta can't help but feel a little sad about her outing with Catherine coming to an end and heading back to Lakeview. She currently feels quite at home living at Lakeview, but she initially felt slightly resistant to the restrictive choices of retirement homes short-listed by Catherine. She thinks to herself as she looks out the window, *"I think she did a lot of investigating ahead of time, on her own, but I think I would really like to be in from the beginning, not to have sorted out and choices made for me to choose from, but then she didn't have much time. I think the circumstances are that the choices had to be made quickly. So I really, in way, couldn't fault her for that"*.

Catherine drives on to Lakeview's circular drive way and parks near the front door. With Catherine's help, Loretta hesitantly steps out of the car. Every step she takes toward the facility with her cane feels like she is closer and closer to losing her freedom and independence once again. She knows she is constantly under surveillance and feels like a sheep just sort of being herded. Without Catherine, it is not easy to gain that freedom again. After living here for quite some time, Loretta knows her boundaries. She knows there are certain limitations on decisions she can make. She cannot just decide to take off. She has to let somebody know that she is with someone that she can depend on. She takes a deep breath and says to herself, "well, I have already adjusted to this routine" and together they walk into the facility.

"Hi Sandy, I' m here to sign Mom back in."

"HI CATHERINE, YOU WILL NEED TO SIGN HER BACK IN. YOU ARE BACK JUST IN TIME WITH HER; DINNER SERVICE IS ABOUT TO START AND IT IS ALMOST TIME TO TAKE HER MEDICATION."

"Yes and I would like to have dinner here with my Mom tonight, if that' s alright."

"I WILL NEED TO GIVE THE DIETARY MANAGER A CALL TO SEE IF THIS LAST MINUTE REQUEST CAN BE MADE. NEXT TIME, PLEASE LET US KNOW IN ADVANCE. IT CAN BE QUITE A HASSLE FOR THE DIETARY STAFF TO ORGANIZE SEATING ARRANGEMENTS WHEN THEY ARE ALREADY BUSY TO SERVE RESIDENTS ON TIME. IF YOU LET US KNOW NEXT TIME APPROXIMATELY WHEN YOU WILL BE RETURNING WHEN YOU SIGN HER OUT, WE CAN MAKE SURE LORETTA GETS HER MEDICATION ON TIME."

This section looked backward and forward into Loretta's feelings and thoughts about living at the retirement home: from feeling reluctant to move out to feeling at home living at Lakeview, and from feeling left out to beginning to realize that Lakeview was her home. It is evident that Loretta got progressively resilient about the changes that she experienced as she transitioned to living at Lakeview because she learned to look on the better side of the situation with an accepting attitude. She focused on the positive gains she got from the situation, which was having a caring daughter who was always there to make sure her needs were met and her accommodation was well taken care of.

Having to sign in and out of the facility and having a scheduled routine illustrated the confined situation that she was in, in comparison to the freedom she had living alone at home. It was another change that she learned to adjust to. It was sensed from her tone of voice that she was not completely satisfied with the whole transition process to the retirement home, but Loretta was able to bounce back and prevent herself from dwelling on the negative thoughts and moved forward.

5.2.7 Tablemates

After receiving the dietary manager's confirmation for Catherine to dine in with Loretta, the receptionist guided them to a dining table that was reserved for residents who are eating with guests. Even though Loretta usually had an assigned seat, she got the privilege to sit at a table for two to engage in more private conversation with Catherine.

“Mom, a few weeks ago I asked the recreation therapist to arrange for you to sit with other tablemates. How are you enjoying sitting with your new table mates?”

“It’s a lot better now. I’m able to have some conversation with my new table mates and really enjoying their presence and sense of companionship.”

“What do you talk about?”

“Oh we exchange news and compare what is going on in our lives, that sort of drew everybody together. Instead of just picking on someone to speak, we just let each other speak. We don’t want to shave the other person out, or else there’s no catching up then after that. But I use a lot of my counselling skills. So I think now dining here has become more enjoyable and at ease.”

“That’s great, Mom! I’m glad the reassignment worked out. I knew how unhappy you were sitting with your old table mates.”

“You’re right. I initially struggled just to tolerate their table manners. I knew I was a nitpicker, but I had to keep reminding myself, I’ve gotta be tolerant, I’ve got to learn to ignore it. It was tough, but I eventually was able to be more accepting as long as it didn’t affect me. Even so, they weren’t very sociable. I know as a councillor that Alzheimer’s tends to make people withdraw,

so I tried to be more sociable and friendly, but our conversations were kept at a superficial level and I wouldn't really consider them to be a supportive group. It just took some time to get used to, because the level of connection I tried to establish with them was not nearly as genuine and deep as the connection I have with you."

Situated in a dining room that Loretta regularly dined in everyday, the interactions and experience was very different when Catherine was present. With Catherine, the routine of sitting with tablemates was broken and the quality of the social interaction enhanced from being superficial to meaningful. Transitioned from eating only with Catherine at home, Loretta needed to learn to accept her tablemate's table manners and idiosyncrasies that she might not agree with. Eating together at assigned tables could be the best or worst experience in LTC, dependent on compatibility with tablemates. Loretta used her counselling skills from her past work roles to enhance her mealtime experience as well as the others at her new table, and made the best out of the situation despite the weak social connection established with her old tablemates. However, she was delighted with her new tablemates who were more to her liking, demonstrating the importance of this connection for her continued resilience in the retirement home.

Loretta's attempts to establish a connection with her tablemates could be contrasted with the connection she had with Catherine in this section of the story, which

was imbued with depth and feelings, rather than the superficial small talk Loretta tried to engage in even with her new tablemates. This again showed the special mother and daughter connection that this dyad had and how this helped to build resilience in the face of transitioning to a retirement home.

5.2.8 Continual Progression of Dementia

“Mom, what would you like to eat tonight? They are serving chicken parmesan and meatloaf. I think you will really like the meatloaf, you mentioned to me you really like their meatloaf here.”

Without hesitation, Loretta chooses what Catherine chooses. After they placed their order, Catherine and Loretta continue to reminisce, this time about their secret quilting project they worked on together for Loretta’s grandchildren. They enjoyed the process of working on a project together, from talking, dreaming, and planning-- it had been their little secret. Participating in the quilting project with Catherine was important to Loretta because it helped her cope with the changes of living with relative strangers in the retirement home by holding on to the past and something that was her own, outside of the home.

“Mom, I gave Brandon and Claire their quilts and they absolutely love them! Claire especially loves the little flowers on hers.”

“Oh that’s great! I’m glad our hard work paid off” Loretta replies as she watches the personal support worker place a meatloaf meal in front of both of them, with a side of glazed baby carrots and mashed potatoes.

Catherine isn't particularly enjoying the food, but she is enjoying bringing happiness to Loretta. She reiterated the news about giving the quilts to her grandchildren several times before, and she gets the same positive response from Loretta every time. Catherine takes a bite out of the meatloaf and thinks to herself, "I can talk about anything - without the expectation that she's gonna retain it, or act on it, or remember it. And I can give her the same good news over and over again. Like I ran into a mutual friend of ours just last week and I was able to tell her that three or four times and it was great news every time"!

A nurse comes by and hands over a little white pill and says, "Here's your medication, Loretta".

"Oh I nearly forgot! Well, that shouldn't be a surprise!"

They all laugh and Catherine is relieved to know that it is getting to the point where Loretta is a little more comfortable telling people that she has trouble remembering, but for awhile, she felt like she was covering for her. Now it is more like she is just helping her in a much more open way. When Daniel's family comes to have dinner with them, Catherine needs to keep in mind to always involve her in the conversation, but also to try to slow things down, repeat, and rephrase. If not, the conversation would be too busy and complicated for her. She provides all the help she can but tries to always balance out helping over embarrassing her.

"Mom, do you need any help with cutting up the meatloaf? I know your eyesight hasn't been very good lately."

"That's ok, I'm sure I can manage."

"Alright, Mom. Take your time."

This section of the story validated their intimate mother-daughter relationship, where they had a clear understanding of each other's wants and needs, what would make each other happy, as well as having shared activities that best friends would have. This type of relationship was clear from the beginning of the story and has been maintained from the past to the present moment in the narrative. Catherine reiterates stories that she knows will make Loretta happy demonstrating not only her patient quality as a care partner, but that it is more important that Loretta is happy. It is still a gratifying connection that is being established when Loretta's memory problems mean that she can relive a pleasant event re-told in story by Catherine, bringing instant happiness every time. Rather than dwelling on the negative dementia that allows for this, Catherine sees it as a strategy for conversation and improving her mother's well-being.

Loretta showed resilience over her progressive condition by outwardly expressing her acceptance of her memory problems through humour with the person providing her medication. Part of being able to adapt as a care partner is being able to recognize the person with dementia's rate of change as the condition progresses, as well as their acceptance and what is meaningful to them. This was a very valuable trait that Catherine possessed-- to have the ability to change her way of caring for Loretta depending on Loretta's rate of adaptation. It was Catherine's way of being flexible to Loretta's needs as she continued to live with dementia. It could also be seen as this dyad adapting to the new normal together.

5.2.9 Two days later...

Catherine knocks on Loretta's door and finds her looking out the window, as if she is deep in thought.

"Catherine! What are you doing here?"

"Mom, Daniel's family is coming to visit! We've decided to go to my house and make a hearty home cooked meal instead of going out to eat Chinese buffet, how does that sound?"

"Oh, I haven't cooked in such a long time! I would love to!"

Back at Catherine's house, she already has all the ingredients set out, ready to make seafood primavera.

"Mom, can you fill this pot with water and put it to boil on the stove so we can cook the spaghetti?"

Loretta puts the pot in the sink and fills the pot with water.

"What do I do now?"

"If you can, put the pot of water on the stove and turn on the stove so we can boil the water."

Loretta puts the pot on the stove and stares at the dials on the stove.

"...What do I do now?"

Catherine catches on to Loretta's struggle with the stove and for the remaining time they work together to prepare the meal, Catherine patiently provides more repetitive and step-by-step

direction. Catherine's role transitions toward prompting and guiding and letting her mother do each step as she is able and not intervening unless there is a problem.

As she is putting pasta in the boiling water, Loretta makes up her mind to do what she can, and believes she can do more than she does -- she just has got to keep trying. Catherine intently watches Loretta put pasta in the pot. Catherine reflects on her life, realizing that caring for a parent with dementia does impinge on her life and prevent her from doing personal things. However, she puts a positive spin on it and thinks about how given Loretta's reality and their priorities it is about doing as much as she can with what she has got. Catherine feels a sudden sense of appreciation for what she has at the present time understanding that living without expectations for Loretta is freeing. Something special may happen today that provides new memories, laughter and gratification for their relationship. Together they look for the good in the new normal and focus on the enjoyment of having mealtimes together.

By the end of the preparation, dirty pots and dishes are piled up high. To Catherine's amusement, Loretta willingly says, *'Oh goodie, I never get to do dishes anymore'* and jumps right into the task, pushing her sleeves up and turns to Loretta.

"What do I do next?"

The situation of this dyad cooking a meal together reveals Loretta's deteriorating cognitive abilities as the story progressed. Nonetheless, Catherine continued to adapt to Loretta's changing needs and incorporated shared activities to take her out of the routine of the retirement home. Dealing with changes and being resilient means being able to work with any unexpected situations that are thrown at them. Catherine not only adapted to the new normal, but she "looked for the good in the new normal", which

suggests her capability to live her evolving life more fully. Aside from increasing memory problems, Loretta continued to hold on to her previous role as a cook and perform tasks that she felt would bring her happiness and a sense of usefulness. In other words, this section explored Catherine's accepting inner feelings as a care partner and Loretta's short-lived inner feelings as a person living with dementia.

Even though having Loretta be part of the cooking process could potentially slow things down and was more work for Catherine, she acknowledged the importance of having Loretta relive a past pleasure of cooking and being someone who nurtured others through food.

This story, which spanned three days, showed a present view of this dyad's mealtime experience. They reminisced stories, which essentially were stories within a story, showing a past view of this dyad's mealtime experience. Both dimensions together illustrate a temporal picture of their experience from past to the present. The ending of the story concluded with a question, which signified their lives are continuous and evolving, and that this narrative represents only a single time frame of their lives.

5.3 My Life Journey with Chocolate Meringue Pie: Loretta's recipe

1. **Finding a friend and baking mentor:** At age 13, I learned to make pies from my next door neighbour who was a pastry chef. Every two weeks, I packed my bag full of ingredients and headed over to her house and we baked together.
2. **Getting a loyal customer base:** Chocolate meringue pie became my specialty and other people were aware of this. In fact, I acquired 3-4 returning customers. During the tough times, it was a fun way of earning money rather than the way other teenagers often babysat for money.
3. **Recognizing that feeding people nurtures their souls:** I baked pies for people who don't bake. I enjoy baking for others, regardless if I am paid or not. "It is something about feeding people that is very meaningful".
4. **Refining the recipe - Before I got married:** Chocolate meringue pie is a popular dessert to serve for dinner guests. I even get compliments from guests like, "only one woman in ten can make a decent chocolate pie".
5. **Becoming the expert:** With my husband's influence, I enter my chocolate pie at the Markham Fair contest and I got a prize.
6. **Losing my husband and clientele:** After my husband passed away, I moved to live closer to my daughter, Catherine. I no longer have an excuse to bake. I felt like I lost a part of me, however, I am finding the odd family occasion to still make my speciality.
7. **Being told to stop baking:** After I got hurt baking and lost my driver's license, I was told by one of my therapists to stop baking. As much as I am dying to make more pies, I can't bake and deliver my baked goods to share with others. I believe I can still bake, but I don't want to have Catherine worry.
8. **Looking for opportunities to keep baking:** I was admitted to a nursing home and joined the baking-related recreational activities to satisfy my craving to cook and bake. However, sharing the experience with 6-8 people cannot compare with the experience of baking at home where I had the privilege to be involved with every step from start to finish. Not requiring my entire effort to make the pie made the experience less meaningful and nurturing to me.
9. **Finding a partner to bake with:** Catherine knows baking pies is important to me, so she occasionally schedules a block of time to take me back to her house to bake. Even though it is scheduled ahead of time, I always forget, but that's ok, it is a surprise for me every time! It satiates my desire to make a pie and not having to feel like I need to do it all on my own. I'll never say no to making pies!
10. **Finding reasons to bake:** Since no one asks us to make pies, we find opportunities to bake the chocolate meringue pie for others and my daughter will deliver it to them. For example, we bake pies for the drop-in community center and they are always well received. We bake pies to take to our church on occasional Saturday night suppers. We also bake one for my daughter's book club. Everywhere we bring them to, the pies (and us) are showered with compliments. It's not necessarily that someone needs a pie, but it's the other way around. Someone needs to make a pie and for someone who wants to eat it!
11. **Sharing the care of making a pie well:** Catherine sets out the measured ingredients because she is afraid I will lose count. I get to separate the egg yolks and egg whites as well as mix the ingredients even though my hands are a little shaky. If I make any

mistakes, Catherine simply makes a joke about it and somehow we still end up with an edible pie. It is always fun to bake with her.

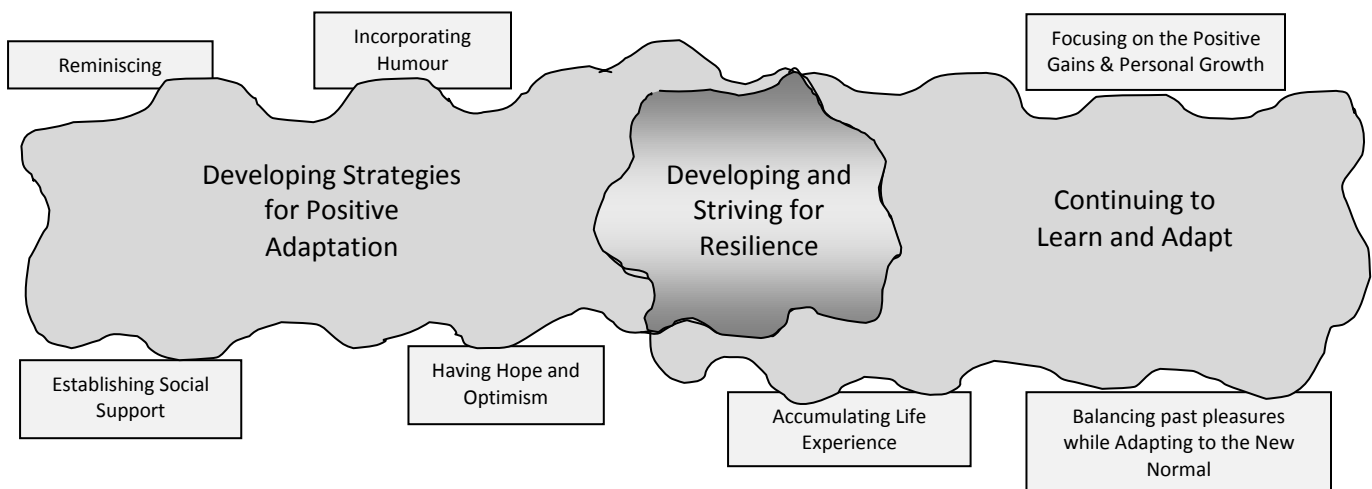
12. **Teaching someone you love to bake:** Catherine is my sous chef and allows me to take the lead. Together, we make sure the recipe is followed and most importantly, we ask each other, “are you sure you put the cornstarch in?”
13. **Taking the time to bake it right:** Making the chocolate meringue pie is a time consuming activity that requires two days to make. The pastry needs to be made the night before and the filling is to be made the next day. I insist that the meringue must not be on the pie overnight! If it was all made in one day, I would not be able to take part in the whole process and Catherine will have to complete the rest of the pie alone.
14. **Being fulfilled by the baking experience:** Catherine wants me to be a part of the whole process of making the pie, from mixing the ingredients to delivering the product. She wants me to experience the gratification of seeing others’ appreciation and happiness for our time and effort for making the pies. To achieve this, she limits the time between the completion of the pie to its delivery -- before I forget that I took part in making it. It is satisfying seeing their eyes widen with excitement when they receive the pie.
15. **Watching someone you love continue the recipe journey and reminisce about the joyful memories:** With my deteriorating vision and decline in dexterity, we continue to make chocolate meringue pies but I am content just to give directions and watch Catherine make the pie. I feel like a teacher. I feel like her 4H leader again, a time when I used to teach her how to bake just as mothers and daughters do. It is satisfying that I am able to pass on my pride and joy to the next generation.

5.4 Constructed Themes

The two narratives presented in this study reflected varying levels of resilience unique to the different points of each dyad's journey. This resilience, in turn, reflects differences in the dyads in terms of internal conditions, relationships, situations, and the progression of dementia. However, the following two major themes on how the dyads developed and strived for resilience were emergent from the narratives: 1) developing strategies for positive adaptation, and 2) continuing to learn and adapt. Subthemes for 'developing positive strategies' include: reminiscing, incorporating humour, establishing social support, and having hope and optimism. Subthemes for 'continuing to learn and adapt' include: focusing on the positive gains and personal growth, balancing past pleasures while adapting to the new normal, and accumulating life experience.

It is my contention that it is essential to combine these two major themes to develop and strive for resilience for families living with dementia. This was illustrated on Figure 1 as two distinct themes that are included at the same level, influencing the development of resilience.

Figure 1: Approaches for Developing and Striving for Resilience



Based on an individual's personal preference and situation, not all strategies will be used, therefore the shading of "Developing and Striving for Resilience" is not uniform. The squiggly lines represent the ebb and flow of the ongoing path to develop and strive for resilience.

5.4.1 Developing Strategies for Positive Adaptation

Being resilient while living with dementia was a transitional process for our participants. During the process, they developed strategies, including reminiscing, incorporating humour, having hope and optimism, and establishing social support, that helped them achieve acceptance of the evolving condition and increased emotional flexibility to bounce back to a more positive state of mind. Strategies were discrete and often intentional actions to change a situation for the better. Although some families had used these strategies before the journey of dementia began, they were 'exercised' more commonly with the continual changes seen with this syndrome.

5.4.1.1 Reminiscing

Reminiscing was a common theme, as participants enjoyed bringing up past life experiences that brought them positive and negative emotions where meanings were attached. Using this strategy, being resilient is built upon sharing common experiences and emotions that can lead to mutual respect and support. It seemed that even reminiscing together about negative experiences had its benefits as they learned to appreciate the present moment and interpret the negative experiences within a positive context with a having 'lived through it' attitude. This strategy allowed participants to reaffirm their identity as each experience defined who they once were and who they had become. This strategy also stimulated the memory of the persons with dementia by engaging with their remaining physical and cognitive abilities. By remembering, it

provided a sense of reassurance that they knew who they were and that their life-story was still intact. Meals were a common timeframe that participants chose to reminisce as they were face-to-face and conversing while enjoying a meal. Catherine and Loretta's story revolved around the idea of reminiscing because Catherine acknowledged the significance of bringing up events that linked to various emotions and meanings that were important to Loretta. For example, reminiscing about eating dinner together several times a week brought up joyful memories of spending quality time together and Loretta's identity of being a mother who nurtured her daughter through food. Beth and Jeremy always conversed during mealtimes and that included reminiscing. Often times, doing so left them feeling that they were glad to have had the conversation. This means that reminiscing not only supplied the linked emotions to the conversation, but the emotions may linger after the conversation as well. The prolonged positive feelings acted as a positive strategy towards developing resilience.

5.4.1.2 Incorporating Humour

These participants chose to use humour to lighten up tough situations and incorporate joy and laughter in their present moment. Lightening up an adverse situation helped them regain normal levels of functioning more readily after setbacks. For Jeremy, humour was used to cover up the negative feelings from a tough situation and even used to present a strong persona, making light of the situation and that it was easier to handle than perceived. It was seen as a defence mechanism to hide the weak and depressed feelings that initiated from the tough situation. On the other hand, Loretta and Catherine utilized humour and laughter, often originating from a shared experience, and also used this strategy to lighten up the present situation, which could be seen as filled with deficits. For example, Catherine protected Loretta's

dignity by joking about the mistakes that Loretta made while baking together to signify that baking was a shared activity that was done for fun rather than a strict and demanding task. Essentially, humour serves as a vehicle to identify the positive outcomes and diminish negative emotions despite exposure to adversities. Humorous experiences not only brought out joyful emotions, but they also served as a reminder of happy memories shared. Even though mealtimes might not be the only time to incorporate humour, participants in this study could recall humorous and joyful experiences associated with mealtimes, indicating that it was perceived as a positive time.

5.4.1.3 Establishing Social Support

For these participants, the connection the dyads had with each other was their most significant and fulfilling relationship, which gave them the strength to be resilient. In this context, being resilient is built upon solid relationships of deep meaning. They used mealtimes as an excuse to connect with each other and outsiders to support their resilience. For instance, Catherine would drop by Loretta's house a few times a week for dinner. That timeframe provided the opportunity to build connection and support for each other. No matter how big the social circle was, the sense of connection with another, especially within dyads, was significant for all participants to maintain. Having someone to confide in and make decisions with were examples of why social support was important to the participants. Participants also extended their social circle toward others in their church, where people shared similar religious and spiritual practices. Continuing to extend their social circle was an attempt for participants to draw on external resources to manage their daily stress. Even after Beth had lost her significant other, she eventually sought an alternative social connection with friends. Interestingly, Jeremy

utilized food as a way of maintaining his social circle despite a dementia diagnosis, because the act of sharing food and conversation was rewarding in itself. Even in a forced interaction, such as eating with strangers at mealtime, Loretta recognized the benefits of extending her social circle and made conscious efforts to connect with her mealtime tablemates.

5.4.1.4 Having Hope and Optimism

Having hope and optimism was a strategy that involved being able to find positive meaning in any circumstance; being resilient is having the ability to find that silver lining in any situation. With hope and optimism, participants learned to be grateful and appreciate the simpler things in life, such as enjoying a meal or cooking together, despite living with dementia. Participants displayed hopefulness by reframing their way of thinking in a positive direction. For example, rather than seeing a caregiver role as a burden, Catherine saw the role as a way of being needed and relied upon. Jeremy and Beth remained hopeful by putting dementia aside and living as normally as possible. Persons with dementia also displayed persistent behaviours to show that they had hope in their capabilities, such as cooking and being able to go out to eat.

5.4.2 Continuing to Learn and Adapt

Living with dementia is a dynamic process that occurs over a significant time span. During this process, participants naturally learned and adapted to the unfolding changes as dementia progressed, so that they could develop and strive for resilience, allowing them to better manage their individual situations. Three subthemes described this continual learning and adaptation—focusing on the positive gains and their personal growth, balancing past pleasures,

and accumulating life experience. These are not considered strategies so much as a philosophy of how to live the journey with dementia, adapting to a new way of being.

5.4.2.1 Focusing on the Positive Gains and Personal Growth

Participants experienced a degree of positive gains and personal growth as they continually performed their role for the persons with dementia. This is not to say participants did not experience feelings of strain and stress especially in the midst of change, but over time they had learned to focus on what they had gotten out of every situation. Simple rewards, such as receiving positive feedback and appreciation from the person with dementia was a positive gain that the care partners in this study found fulfilling. For example, Loretta's appreciation for Catherine's support and presence, such as having her to confide in and enjoy meals with, was a positive gain for Catherine because she felt needed and depended upon. Personal growth could be witnessed from all participants from the narratives where they were able to learn and grow from stressful experiences and move towards acceptance. Beth, for example, learned to not take Jeremy's hurtful words personally and accept his evolving changes as dementia progressed. In that process, Beth developed resilience and had a more positive perspective of the change by reminding herself that the changes stemmed from the disease itself, not the person.

5.4.2.2 Balancing Past Pleasures while Adapting to the New Normal

When dyads rebounded from an adversity and moved on with their lives by finding alternatives that created new pleasures and appreciation, they were resilient. It was only natural for participants to hold on to some past pleasurable activities and memories because it provided them with a sense of happiness, familiarity and continuity among the daily changes they

experienced. However, as dementia evolved, some activities had to be put aside. Participants adapted to the new normal by finding alternatives of past pleasures, often a similar activity that could provide equal satisfaction, but was more easily part of the new normal of their life. For example, eating out rather than cooking. Being able to relive past pleasures through reminiscing was a positive strategy discussed above that allowed this balancing out to occur. As well a way of adapting to the new normal was to recognize the remaining abilities of the persons with dementia and incorporate them with a past pleasure. For example, Loretta always had a passion for baking, but due to decreasing abilities, Catherine stepped in to bake with her, and eventually bake in front of her while Loretta used her remaining ability to watch and advise on the baking process. In Loretta's recipe we see that the carrying on of this family tradition was a way of balancing this past pleasure with her new normal. This new normal granted time for them to connect through an activity they both enjoyed.

5.4.2.3 Accumulating Life Experience

Over the six years of data collection, participants described an accumulated life experience of living with dementia. Over time, participants had learned from prior experiences and gradually were more prepared to handle stressors associated with dementia, thus they were more resilient. For example, Beth was initially torn by Jeremy's hurtful words and aggressive behaviours, but she gradually understood from accumulated experience, that these stemmed from the disease itself, and not the person. Participants in this study were middle aged to older adults, where they had accumulated life experiences in general, not only with dementia. Their other life experiences had also taught them to deal with a range of stressors. For example, Beth had an abusive past and had learned in those prior experiences how to deal with hurtful words; she did

this by appreciating the present more and putting those difficult moments aside. She carried this resilience throughout Jeremy's journey with dementia; even near the end of his life, she could deal with the emotional abuse of staff at the residence in a proactive way, rather than giving up. Participants also demonstrated resilience by 'pushing back' or resisting others' expectations, when these were not consistent with their needs and life experiences. For example, Loretta was resistant to follow her daughter's lead on preparing food for a pot luck gathering and went out of her way to take the taxi to buy the ingredients to make the dish she believed others would enjoy. Loretta's accumulated life experience that provided for problem solving and other skills necessary to achieve her goal, allowed her to be resilient in this situation.

Chapter 6: Discussion

This study explored the ebb and flow of mealtime resilience for families living with dementia. Ebb and flow refers to the constant fluctuation that families living with dementia experience as they move through their lives filled with constant changes, just like the decline and increased motion of ocean tides. Using narrative analysis, how they encountered, struggled with, and overcame some problems, while being defeated by others was understood. Through these two narratives and recipe, specific strategies that were used by families with dementia to respond to changes, turning points, and major events were explored. Two themes and several subthemes were identified. These themes are reviewed below in the context of how they relate to our understanding of resilience of older adults in the current literature and specifically, what we can learn from these results around using meals and food as a means of retaining resilience for families living with dementia. I will address the limitations of this research, its strengths and the implications for managing life's adversities through mealtimes while living with dementia.

6.1 Developing Strategies for Positive Adaptation

Resilience is what determines the odds of people doing well while overcoming hardships and facing obstacles (Hildon, 2008); one of the ways to develop resilience upon exposure to adversity is to develop positive strategies. As found in this study, strategies are approaches used for positive adaptation in the face of adversity. The following subsections are discussions of the positive strategies that were presented in the stories of the dyads. Those revealed in this study were relatively consistent with the strategies described in the current literature.

6.1.1 Reminiscing

Reminiscing, or life review, is known to be therapeutic for older adults to support resilience in those coming to terms with adversities (Resnick, Gwyther, & Roberto, 2011). It is a way of encouraging people with dementia to talk about issues that are meaningful to them. The act of sharing common experiences and memories can develop mutual respect and support (Hagens, Beaman, & Ryan, 2003). Every part of the dyads' stories included sharing their memories and experiences and thus was a key technique for writing their narrative. Having been interviewed could be considered a therapy in itself as they were retelling their history in a meaningful way. Reminiscing is an activity that allows persons with dementia the opportunity for social interaction, and even though experiences recalled may not all be positive, it also helps care partners to appreciate the unique experiences of persons with dementia (Hagens et al., 2003). Reminiscence also allows persons with dementia to be more cognitively engaged rather than having communication with care partners centred on task-oriented topics. This coincides with Loretta and Catherine's story when Catherine utilized reminiscing as a method to stimulate Loretta's memory during a meal.

Reminiscing is a way of coming to a new understanding of the meaning and purpose behind those recalled experiences. According to MacKinlay (2010), this is called spiritual reminiscence. Spiritual reminiscence is a way of retelling a life story while placing a focus on the meanings, which often are associated with the internal conditions behind those experiences such as joy, sadness, anger, or guilt. It is an active coping strategy that reminds us of who we are and were. It is also a way for some families to remain involved in conversation, especially long term memories that could still be recalled by the persons with dementia (Genoe et al., 2010). During the process of retelling a life story, we create and discover our identity and express what it

personally means to us (Resnick, Gwyther & Roberto, 2011, pg.10). This is especially important for persons with dementia to reconnect with their sense of identity, enhance the meaning of their life histories, and even be more open to future changes and development (Coleman & O'Hanlon, 2004; Hugh, Louw, & Sabat, 2006).

The narratives also show how the participants would use mealtimes as a time frame to reminisce. As the stories unfolded, identities surrounding mealtimes were confirmed and even new ones emerged. An example of a confirmed identity was Beth's 'hero' saving the quality of Jeremy's dining experience; she sustained this identity until the point of his death. An example of an identity that was not brought up until reminiscence occurred was when Catherine claimed Loretta as her sounding board during mealtimes when Catherine needed someone to listen to her story and confide with. Essentially, this study demonstrated that mealtimes provided an opportunity to share life stories and authenticate identities. By doing so, participants engaged in the process of "becoming" by coming to terms with how far they had come through the illness and their shift in self-identity. This is consistent with findings from the Eating Together study by Genoe et al. (2010) stating that mealtime not only is a time to honour individual and family identities, but also promote evolving identities; it could be done by respecting one's roles, capabilities, choices, and preferences (Genoe, et al., 2010). Honouring evolving identities could lead to various positive feelings such as worth, self-esteem, and pride.

6.1.2 Incorporating Humour

It has been explained by Garcia (2006) that humour is a cognitive construct that links to joy and hope. It is common for individuals to use humour in various extents, but those with greater tendencies to cope using humour report greater daily positive mood and keep depression

from taking over (Lefcourt, 2001; Resnick, et al., 2011). In this study, it appeared that humour was used across dyads but for different purposes. It confirmed other research that states that laughter generates positive emotions and also helps to cope with stressful situations (Tugade, 2004). In this study, laughter was generated through reminiscence of humorous life incidents and joking about future expectations. Doing so, allowed participants to temporarily gear their thoughts away from a stressful situation and remind each other of shared moments that were deemed joyful. On the other hand, humour was also used in the narrative as a defence mechanism, as a way of coping with stressful situations. Not only did it help to lighten up the severity of the situation, but it was also a method of displaying to others that they were able to cope with dementia with ease. In other words, resilience not only links to positive adaptation, but also the avoidance of negative adaptation in the context of adversities or risks that cause threats to good adaptation (Kaplan, 2006; Wright & Masten, 2006; & Rutter, 2007). It is, however, unfortunate that there is limited research to explore the therapeutic effects of humour.

Humour can be a subjective strategy to use and the effectiveness is individualized and time sensitive. Keller et al. (2010) have found mealtimes to be a time to promote emotional support; part of providing this emotional support is laughing, joking around, and dispersing negative feelings. This research confirmed that laughter and humour are more than an individual's coping mechanisms; they are also strategies for two or more people to share joy and their burdens in a light-hearted way. As families often take time to eat together and communicate, the structured time of a meal becomes an opportunity to incorporate humour and laughter, allowing them to rebound from adverse feelings, move on with their lives, and thus develop resilience. McGuire, Boyd, and James (1993) recognize the therapeutic effects of

humour for the elderly and suggested attaching a picture at a prominent place (such as the mealtime table) as a reminder and affirmation that laughter is still possible.

6.1.3 Having Hope and Optimism

Hope is a construct that is associated with optimism; it is a positive outlook that research has shown enables older adults to face chronic illness with a positive attitude and a proactive mindset (Rybarczk et al., 2012). All participants in this study demonstrated hope and optimism while living with dementia, but in varying levels as stressful situations emerged overtime. Having hope enabled them to reframe a situation and engage in proactive self-management. With that being said, participants took time to develop the resiliency to be optimistic. In the process of being resilient, participants took proactive measures to meet goals and had the willingness to engage in the process. For example, Beth had the ultimate goal of providing unconditional care for Jeremy. This included ensuring that he had enjoyable dining experiences. She persistently advocated for him demonstrating a proactive mindset to improve every situation she encountered. Even though she struggled to be optimistic, her determined efforts showed that she had hope to improve every situation, especially when it involved Jeremy's quality of mealtime. This coincides with Seligman's (1991) definition of Dispositional Optimism, which is positively reframing a situation and focusing on taking action to improve a situation rather than being inactive.

Sometimes when hope cannot be found from within, individuals might seek external sources for hope. As written in the narratives, the participants in this study found hope in their faith. In research looking at spiritual growth and faith among caregivers, it was revealed that their sense of spirituality and faith served as a source of comfort or a buffer from the stressful

role of care giving. Several participants felt “re-energized” after turning to their faith (Sanders, 2005). In this study, Beth found her faith to be a form of relief from the stressful role of care giving and gave her hope. The sense of spirituality provided meaning and opportunities for healing.

6.1.4 Establishing Social Support

A study by Wilks and associates (2011) which assessed the impact of Alzheimer’s patients’ aggressive behaviour on caregiver coping strategies and resilience reported that task-focused coping was the most commonly chosen strategy among caregivers to promote resilience. The two most successful task-focused examples include religious/spiritual practices and social support (Wilks, Little, Gough, & Spurlock, 2011). Other resilience literature also stressed the value of social support (Masten, 2001; Rew, Taylor-Seehafer, Thomas & Yockey, 2001) and its importance in finding meaning while living with the illness (Pentz, 2005). This study is consistent with the literature that indicates that social support is crucial for those living with dementia, specifically the social relationship each in the dyad had with the other. Expanding the social circle was equally important; Pentz (2005) noted that those who have higher levels of social support have more positive attitudes in life. An example of this was when Beth lost her partner due to dementia, one of the biggest factors that lifted her up and helped her cope was being able to eat out with her church friends. She would temporarily set her grief aside and not dwell on setbacks. Participants also exchange support at mealtimes, because eating with others is an emotionally supportive activity (Keller et al., 2010). By reading the narratives, it was evident that there was a constant exchange of support with others, and mealtimes specifically provided a time frame to share the support and strive toward adaptational success.

Part of providing social support is to also providing emotional support, such as showing gratitude and appreciation. Showing gratitude and appreciation was shown to be a way to be resilient in this study. Two participants in Pentz (2005)'s study mentioned that the kindness of others and the little favours they did for them helped to manage their day-to-day activities. This idea was readily shown in this study where mutual gratitude was displayed within each dyad. Cooking, for example, symbolized an act of nurturing another. There was a sense of appreciation to be nurtured and cared for, and consequently the participant who cooked the meal received positive feedback and was appreciated. In other words, mealtimes served as an occasion for achieving reciprocal rewards even though families living with dementia also continue to experience challenging occurrences. Similarly, findings in the Eating Together study found that for some participants who had the role of food preparation, their efforts were often appreciated and this reward provided an emotional boost (Keller et al., 2010). However, this type of emotional support within the dyad diminished for one of the families in this narrative analysis when dementia advanced. It was therefore important that the dyad had additional external support when reciprocity was lost.

6.2 Continuing to Learn and Adapt

A strength of doing this narrative analysis was the ability to observe the transitions and change that participants experienced overtime. The second major theme constructed out of this study is from being able to witness the development of resilience in a longitudinal manner. The following subsections are discussions of subthemes of continuing to learn and adapt while living with dementia.

6.2.1 Focusing on the Positive Gains and Personal Growth

The term 'positive gain' refers to the appraisal of how a change resulted in enhancing an individual's life (Kramer, 1997, p.219). Examples of gains that the literature has found from caregivers' reports include: reminiscing, sharing activities, and enjoying each other's company (Butcher, Holkup, & Buckwaler, 2001). In this study, Catherine acknowledged the positive gains of performing the care partner role, including having the opportunity to cherish her relationship with her mother, and the satisfaction of being appreciated and the fulfillment of being depended upon to provide care and support. The obligation to provide care would occasionally cause moments of emotional stress and strain, but the positive gains that surfaced from this obligation were rewarding enough to achieve resilience for participants. According to Butcher et al. (2001), it is common for caregivers to experience mixed feelings of strains and gains. As dementia progressed, the personal gains might not always be as apparent. For example, Jeremy was no longer expressive of his appreciation for Beth's efforts to take him out to eat at his favourite restaurant as his condition worsened. However, her successful efforts to maintain Jeremy's quality of life were already a reward and fostered the maintenance of her resilience. The participants' stories were a form of quest narrative (Frank, 1997), which involved people journeying through adversities while holding on to the belief that something is to be gained from the experience. There is a sense of resilience in quest narratives because participants seek for alternative ways of being well (Frank, 1997, pg. 115)

The term personal growth, in the context of caregivers, is defined as a process of becoming more caring and connected towards others and re-evaluating what is really important and meaningful in life (Hogan & Schmidt, 2002, p.617). Through difficult life events, it was believed that growth could emerge if the individual could reframe the situation into more

positive terms. Beth demonstrated personal growth after Jeremy's condition took a turn for the worse. Where she initially experienced sadness and frustration for the change in his behaviour, she grew to learn that the behaviour stemmed from the disease and she re-evaluated the importance of maintaining trust and connection with her husband rather than dwelling on the pain. Essentially, she grew from the experience, not merely surviving. This coincides with Kralik and associate's (2006) research stating that the concept of resilience is not merely surviving the adversities, but it also includes growing or even thriving and benefiting from the experience (Kralik et al., 2006).

6.2.2 Balancing Past Experiences & Adapting to the New Normal

The key to resilience, as found in these narratives, is balancing losses and adapting to the new normal. As the illness progresses, persons living with dementia may wish to continue with their accustomed lifestyle and habits that they have developed over the years, especially as some of their roles are taken away. According to Menne, Kinney, & Morhardt (2002), persons with dementia have the repeated desire to continue to do as much as they can; this is called Lifestyle Continuity. As described by Menne et al., (2002), some activities gain greater significance over time and it is often realized at the point of loss by the person with dementia, that they have taken the activity for granted. For example, baking had always been a meaningful activity for Loretta. The privilege to bake alone was taken away after an accident. Catherine helped Loretta adapt to a new normal by attending baking activities at the retirement home and finding time to bake with her outside of the facility. This process is defined as "sliding into food roles" where food preparation roles have gradually shifted as the person with the new role learns to adapt to the additional responsibilities while the person losing the role, learns to let-go (Atta-Konadu et al.,

2011). The new normal would never be the same as before, but modified activities could help to maintain some level of continuity with the pre-dementia lifestyle. Fundamentally, mealtime activities offer room and flexibility to transform with the changes and adapt to the new normal. This idea corresponds with an exploration of the adjustments made to mealtime changes within the context of dementia, where it was shown that families settled for innovative ways of doing things during mealtimes to retain the valued aspects (Genoe et al., 2012).

6.2.3 Accumulating Life Experiences

Older adults experience more chronic health issues than younger adults, and these accumulated life experiences are commonly mentioned as a significant reason for why older adults cope better when dealing with health problems (Rybarczk et al., 2012). In other words, older adults have lived through more negative experiences and are more prepared to handle future stressors because they have developed more effective stress management skills. Most participants in this study, particularly the caregivers, developed resilience to certain stressful situations based on past experiences. For example, Beth learned what triggered her husband's aggressive behaviour and actively developed strategies to avoid similar problems in the future. It is believed that an individual cannot claim to have developed resilience unless they have experienced adversity (Kralik et al., 2006). This is true from these narratives and it is expected that all persons with dementia and their care partners have capacity for resiliency due to their experiences, with the only exception being persons with severe dementia for whom almost all of the past, and their experiences, are absent.

6.3 Theoretical Framework for Change and Resiliency

This study was guided by the Thriving Model (Haight et al., 2002) and the FAAR model (Patterson, 1988). The findings in this study help us to understand further with these two frameworks. Complete failure to thrive and perfect thriving, as explained in the Thriving Model could similarly be compared to low resiliency and high resiliency, respectively. This model was illustrated as a continuum, which coincided with the findings of this study that participants' resilience development continually fluctuated because it was a dynamic process. The major themes and subthemes found in this study equates to the 'contributors' of this model, because they were variables that could enhance an individual's way of thriving. This could be illustrated with the 'panoramic puzzle' analogy where participants could pick and choose puzzle pieces of strategies to flow with the ongoing changes that unfolded as life progressed. The FAAR model suggested going through the adjustment and adaptation phases to achieve homeostasis when changes occur. The strategies found in this study fitted into the adaptation phase because families utilize the strategies to achieve a balance. These two phases gave families a chance to learn and grow from each crisis situation. The panoramic puzzle could continue to be pieced together, illustrating a road toward resilience. However, rather than suggesting that homeostasis is achieved, this study found that resilience ebbed and flowed and that there was a continual striving to develop resilience.

6.4 Summary of Discussion

Developing strategies for positive adaptation is essential to develop resilience because they promote a sense of positivity and a "pick-me-up" from stressful experiences. However, having these strategies is not enough to develop resilience over time because this process is

dynamic. It is also then necessary to continually learn and adapt during the ongoing process of living with dementia; this mindset appears to be necessary for resilience. Subthemes of this major theme do not involve strategies that necessarily provide a sudden sense of positivity, but over time it is a way of being able to more successfully manage adverse situations. This theme was more readily detected in this narrative analysis, as compared to prior work, due to the nature of analyzing longitudinally.

It is evident that the interpretations in this study are relatively consistent with prior studies in terms of how older adults develop resilience when dealing with chronic diseases. However, studies looking at the resiliency demonstrated during mealtimes are very limited. The Eating Together study (Genoe et al., 2010; Keller et al., 2010) provided an opportunity to explore this topic, and this specific study was an extension to the Eating Together study where it was able to provide a more longitudinal view. The narrative perspective is able to show the transition and changes in resilience among the participants over time which is currently absent in the analysis to date of the Eating Together study.

6.5 Strengths and Limitations of this Study

This study includes two narratives, and as such it may be traditionally seen as a limitation with a small sample size of only two dyads, or four participants. However, narrative analysis is not meant to be used for large numbers because the method requires attention to fine analytic details such as organization of a response, nuances of speech, and what can and cannot be spoken on specific experiences rather than seeking an easy and unobstructed view of subjects' lives (Reissman, 1993). It is the uniqueness of identities, intentions, and feelings of subjects revealed in particular experiences that are the focus (Holloway, 2005). Although narratives are not

necessarily designed to be generalizable, the issues addressed and ideas developed around resilience are believed to be transferable to others that are living with this same syndrome. However, limiting the inclusion of Caucasian dyads of an Anglo-Saxon background likely flavoured the presentation of resilience at mealtimes for families living with dementia; further work should explore resilience at mealtimes in other cultural groups.

Yet the voices heard in the stories have added to our understanding of what it is like for some family members living with dementia, as current literature based on narrative analysis is uncommon in the nutrition field. The two dyads were purposefully chosen to be different in the gender of the person with dementia, as well as the relationship within the dyad. This difference provided insight to the significance of gender and relationship roles of living with dementia during mealtimes. It could also add to the results found by Atta-Konadu et al. (2011) which looked at the gender roles of spousal male care partners and their wives with dementia during mealtimes.

Another limitation of this study is the use of secondary data. I had not met or interviewed the participants in this study and this could have influenced my portrayal of their experiences. For example, changes in the tones of voice or nonverbal cues could be captured physically during interviews that I could not capture from reading transcripts. However, as a researcher using a social constructionism theoretical framework, I have identified that the reality of the participants' stories was a subjective meaning-making process that was created by the interaction between myself and the transcripts. To increase the trustworthiness of my analysis, I also had the help of the interviewers to read over my analysis to reduce the intensified biases that secondary analysis could be subject to. I also acknowledged my potential biases at the outset of the work

and attempted to identify when they were leading my interpretation that was not fully grounded in the data.

Despite these limitations, this study had the strength of identifying the ebb and flow of participants' resilience as they encountered obstacle after obstacle, allowing some readers to resonate with the narratives and gain insight into their experiences overtime. A storytelling format creates that resonance with visual images and connects with readers as the story unfolds, which helps to gain insight into dyads' experiences. Thematic narrative analysis is a methodology that is not commonly used in research related to nutrition, so this study provided a different lens to the mealtime experiences for families as dementia progressed. The narratives provided six consecutive years of experiences, as well as previous years as participants provided additional information of what happened in their past life. Such in-depth data provides a strong foundation for the narratives produced because the story could illustrate the resilient changes that participants experienced overtime. As well, the narrative is based on a longitudinal data collection. It is built on different stages of dementia and the varying levels of resilience described by the dyads. Having multiple interviews with the same participants allowed interviewers to verify responses from previous interviews, strengthening the trustworthiness of the data. Also, having multiple interviews where similar questions were asked also allowed for confirmation on what was meaningful to the participants year after year. Lastly, the triangulation of interviews provided different views of the participants' experiences. Even participants within the same dyad could narrate the same experience differently at different points in time or during different interviews. This provided an opportunity to understand what was most important in the story as it was told and the key issues that needed to be included in my narrative of this experience. This

method of cross-examination strengthened the study by allowing myself to retell the stories in a more fulsome way.

The themes that were co-constructed from the data are discussed in prior work, but the narrative presentation provides a deeper understanding and elaboration than seen to date. Four researchers were involved in the analysis process of this study, further increasing the rigour; having multiple researchers involved in the analysis process aided in the development of unified themes and concepts. The inclusion of more than one dyad in analysis also provides greater trustworthiness in the themes developed. Lastly, this study was able to connect the dots between the resilience of living with dementia and how it ties in to the significance of mealtimes. This adds to the analysis conducted to date of the Eating Together study as well as adding to current literature. The implication for this connection will be addressed in the next section.

6.6 Implications and Direction for Future Research

The interpretations of this study propose some practical and theoretical implications to enhance the development of resilience for families living with dementia. Social workers, dietitians, or other health care professionals may be in a position to offer counselling for families living with dementia. They can advise that mealtimes are an appropriate point in the day to develop positive strategies and practice learning and adapting to the new normal. Results of this research may help to resolve negative feelings and deal with ongoing changes and responsibilities through developing positive strategies and continuing to learn and adapt. Considering the therapeutic effects of reminiscing and retelling past life experiences, especially over a meal, it may be effective to incorporate this strategy in supporting families with dementia. Educating care partners, persons with dementia, and related health professionals on the importance of mealtimes could change perspectives and thus affect resilience. In addition, it is

recommended to create interventions that promote resilience at an individual level (such as reminiscence therapy to indicate coherence and meaning to the adverse experiences) and at a community level (such as increased access to social support for those in need of alleviating burden). We need theories conceptualizing resilience to recognize the significance of mealtimes for families' well-being while living with dementia. In addition, theories could look into the resilience of dyads as a whole and how they experience changes together during mealtimes rather than individual experiences of care partners or persons with dementia. In essence, this study contributed to the theory of resilience by looking at:

- Recognizing the significance of mealtimes for families' well-being while living with dementia
- Developing theories that extend our view of resilience, by seeing the family as a whole and how they experience changes together during the mealtimes rather than individual experiences of care partners or persons with dementia
- Acknowledging the dynamic process of developing resilience and the continuous ebb and flow of the journey

As well, the results of this study opened up other potential areas for future research. For example, further research might explore mealtime resilience with participants who are more socially and economically disadvantaged, or those of other cultural backgrounds. Another potential idea is to continue using thematic narrative analysis to analyze more families living with dementia and determine if additional themes would be created; this could serve as a basis for a theory of mealtime resilience. More research on the mentioned strategies can be conducted, such as using humour, to determine the significance and effectiveness this strategy has on developing resilience, specifically for families living with dementia.

Finally, practical applications of this research could include using these narratives and recipe as tools to education persons with dementia, care partners and health and social service professionals on resilience and the importance of mealtimes. Stories have a way of staying with an individual in a manner different from facts (Frank, 2010). Storytelling, using the fairytale of Beth and Jeremy or the biography of Catherine and Loretta has the potential to reach various audiences in different ways as they may see something of their own experience in the stories told.

6.7 Conclusion

This qualitative study examined how families living with dementia develop resilience during mealtimes. Developing positive strategies and continuing to learn and adapt were the two common approaches used by participants in this study to achieve this end. Reminiscing, incorporating humour, having hope and optimism, and establishing social support were positive strategies that helped these two dyads achieve an active state of resilience. Participants continued to learn and adapt by focusing on the positive gains and personal growth, accumulating life experiences, and balancing past pleasures while adapting to the new normal. The interpretations presented in the Results and Discussion provide some insight into mealtime resilience for families living with dementia. Specifically, this resulted in the restorying of participants' mealtime experience within the realm of resilience. Restorying participant's experiences showed this ebb and flow and how participants develop and strive for resilience as they experience ongoing changes and transitions during mealtimes. I believe that assessing and mentoring the use of the positive strategies to develop and strive for resilience during mealtimes will be helpful for care partners and health professionals. Assessing mealtime strategies could be useful to identify

where improvements could be made to help families adapt to adversities. In addition, assessing the long term effectiveness of these strategies would be useful to determine if they could maintain and further develop resilience. Lastly, the use of stories themselves could be helpful to reveal to others a side of dementia that may not have been considered otherwise using other clinical or research methods.

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APPENDIX: RESEARCH ETHICS BOARD

Certification of Ethical Acceptability of Research Involving Human Participants

APPROVAL PERIOD: April 7, 2011 to April 7, 2012

REB NUMBER: 11AP005

TYPE OF REVIEW: Delegated Type 2

RESPONSIBLE FACULTY: HEATHER KELLER

DEPARTMENT: Family Relations & Applied Nutrition

SPONSOR: SSHRC STANDARD RESEARCH GRANT

TITLE OF PROJECT: **The Stories of Change in the Mealtime Experiences Of Families Living with Dementia**

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-council Policy Statement requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

Membership of the Research Ethics Board: M. Bowring, *CME*; F. Caldwell, *Physician (alt)*; J. Clark, *PoliSci (alt)*; J. Dwyer, *FRAN*; M. Dwyer, *Legal*; D. Dyck, *CBS*; D. Emslie, *Physician*; M. Fairburn, *Ext.*; J. Hacker-Wright, *Ethics*; G. Holloway, *CBS (alt)*; V. Kanetkar, *CME (alt)*; L. Kuczynski, *FRAN (alt)*; S. Lachapelle, *COA*; L. Mann, *Ext.*; J. Minogue, *EHS*; P. Saunders, *Alter. Health Care*; S. Singer, *COA (alt)*; L. Son Hing, *Psychology*; V. Shalla, *SOAN (alt)*; L. Spriet, *CBS*; L. Trick, *Chair*; T. Turner, *SOAN*; L. Vallis, *CBS (alt)*.

Approved:
per
Chair, Research Ethics Board

Date: _____

