

1-1-2008

Serving up mealtime strategies : how families experience dementia in the community

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**SERVING UP MEALTIME STRATEGIES: HOW FAMILIES
EXPERIENCE DEMENTIA IN THE COMMUNITY**

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2008

By

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Bachelor of Science in Nursing, McMaster University, 2006

A thesis

presented to Ryerson University

in partial fulfillment of the

requirements for the degree of

Master of Nursing

in the Program of Nursing

Toronto, Ontario, Canada, 2008

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Author's Declaration

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Abstract

SERVING UP MEALTIME STRATEGIES: HOW FAMILIES EXPERIENCE DEMENTIA IN THE COMMUNITY

Abigail Wickson

MN, Nursing, Ryerson University, 2008

The mealtime experiences for people with dementia and their caregivers living in the community has not been extensively explored. An existing data set provided information on the mealtime strategies used to cope with changing dementia behaviours. A secondary analysis of data from 10 dyads of people with dementia and their caregivers were analyzed. Four categories were identified including: Strategies to Facilitate Eating; Strategies to Promote a Sense of Self; Strategies to Minimize Risk; and Strategies to Promote Caregiver Well-Being. The dyads used a variety of strategies that were common to all stages of dementia; however by the late stages, the dyads used more specific strategies. In general, the mealtime strategies used by adult caregivers and spousal caregivers did not greatly differ but rather the context in which they engaged in mealtimes did. The results demonstrated that there are opportunities to educate families and professionals about potential mealtime strategies.

Acknowledgement

I would like to acknowledge my thesis supervisor, Dr. Lori Schindel Martin, a woman whose passion and dedication to the improvement of the lives of people with dementia is truly an inspiration to me. I would like to express my deepest appreciation to her, for her encouragement of my pursuit of graduate studies and thesis work. I would like to thank her for all of the time that she has spent guiding me through the thesis process and sharing her expertise and ideas. I would also like to thank the other members of my thesis committee: Dr. Nadine Janes and Dr. Sherry Espin for all of the wisdom they imparted on me through their insightful comments and questions during my planning and writing process. I would also like to acknowledge and thank the other members of the *Eating together in families with dementia: A longitudinal analysis* study, Dr. Heather Keller and Dr. Sherry Dupuis, for allowing me to gain access to their collected data so I could engage in my secondary analysis.

I would also like to take this opportunity to recognize my family and friends. I would like to thank Yvette Haars for all of the assistance that she provided in the refinement of this thesis. I would also like to thank my parents, Chuck and Carol Wickson, my twin pillars of support, for their continued encouragement. Finally, I would like to thank Cory, my fiancé, for his love, patience and understanding during my graduate studies and thesis work.

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Chapter One: Background

Chapter one introduces the background information on Alzheimer's disease and related dementias (ADRD) with a focus on the signs and symptoms as well as the staging of this progressive group of diseases. The information provided in this chapter sets the context for the goals of this thesis.

Currently, there are an estimated 450,000 Canadians over the age of 65 years with ADRD (Alzheimer Society of Canada [ASC], 2007). With the proportion of older persons in the population expected to double by 2031, it is predicted that over 750,000 Canadians will have a diagnosis of ADRD (ASC, 2007; The Daily, 2005). The economic cost of supporting a person with dementia (PWD) is significant (ASC, 2007). The ASC (2007a) reports that an excess of 5.5 billion dollars is annually spent on ADRD, in relation to nursing home care, medications and community support services by paid and unpaid caregiver time.

In addition to financial costs, many people diagnosed with ADRD are living at home and are being cared for by family members (ASC, 2007; Dupuis, Epp & Smale, 2004; Gitlin, Winter, Dennis, Cororan, Schindfeld & Hauk, 2002). As the cost of placing and caring for people with ADRD in institutions increases, and the availability of beds in long-term care homes become scarce due to the increasing older person population, family members are becoming obligated to assume a longer period in the role of primary caregiver in the community (DiBartolo & Soeken, 2003; Hepburn, Tornatore, Center & Ostwald, 2001). Family members who assume an informal caregiving role can experience both emotional and physical strain when caring for family members with ADRD (Canadian Study of Health and Aging Working Group, 1994). Furthermore, caregivers of PWDs experience a great deal of overload that may lead to resentment coupled with a low life satisfaction and sacrifices to their physical and mental health

(Brodaty, Thomson, Thompson, & Fine, 2005; Hepburn et al., 2001). DiBartolo and Soeken explain that family caregivers are responsible for at least 75% of the care in the community setting, and at least 50% of the primary caregivers are spouses of the PWD. One facet of caregiver life in the community may include engaging in the mealtime experience with a PWD. In this case, caregivers may be subjected to an array of challenging behaviours exhibited at mealtime by their family member as his/her dementia progresses, which has been identified as constituting a significant burden (Manthorpe & Watson, 2003; Rivière, Gillette-Guyonnet, Andrieu, Nourhashemi, Lauque & Cantet et al., 2002). Overall, ADRD is a prevalent diagnosis for older people in Canada, with associated social and financial costs. It therefore, deserves the attention of research inquiry with a particular focus on daily life events, such as mealtimes, that can contribute to burden within the caregiver experience.

Dementia Description

Dementia can be broadly defined as “a syndrome of progressive deterioration in multiple cognitive domains, resulting in significant impairment in functioning” (Christensen & White, 2006, pg. 1). This definition of dementia is supported in the literature by Cummings (cited in Dupuis et al., 2004) who identified it as “an acquired syndrome of intellectual impairment produced by brain dysfunction... in at least three of the following spheres of mental activity: language, memory, visuospatial skills, emotion or personality, and cognition” (p.1). According to Dupuis et al., dementia is unique from other forms of cognitive impairment because of its persistent, progressive, and often irreversible deterioration of cognitive function which can be staged from mild to advanced. As a result of a progressive decline in cognitive function, people who are diagnosed with dementia may experience general symptoms including: memory loss, impaired judgment, aphasia, apraxia, agnosia and a change in social behaviours (Gagnon, 1996).

In addition, Pittiglio (2000) explains that due to the decline in memory and cognitive function, a PWD may become socially withdrawn and develop a low self esteem. As a result of the aforementioned signs and symptoms of the disease, eating can present special challenges for a PWD (Manthorpe & Watson, 2003). Chow and McLean (2001) add that the cognitive impairment may become significant enough that the affected person will become dependent on others. As the disease advances, a PWD requires continual assistance with basic activities of daily living (Reisberg & Franssen, 1999), and mealtime should not be considered an exception to this pattern. It is however important to note that the broad signs, symptoms, and outcomes described above are of a general dementia syndrome.

Alzheimer's disease (AD) has received much research attention, and one such outcome has been the development of a staging tool that predicts the course of progression of the disease, not unlike an illness trajectory (Reisberg, 1988). Due to the complexity of an AD diagnosis, the Functional Assessment Staging (FAST Staging) developed by Reisberg allows both practitioners and family caregivers to anticipate the course of functional decline experienced in the person with the AD diagnosis. Table 1 combines Reisberg's FAST Staging with the associated cognitive abilities at each stage of AD (Reisberg, 1984). While the FAST tool was designed for AD, it can be useful to apply the concept of illness trajectory to those clients with related dementias in order to prepare for the functional and cognitive changes that might occur as the disease progresses.

Table 1

Staging of Dementia According to Reisberg

Stage	FAST Stage	Cognitive Abilities
Mild	1. No functional deficiency 2. Forgets location of objects and subjective work difficulties 3. Decreased function in demanding situations or traveling to new locations	May be able to recall own name and name of spouse or children May not be able to remember telephone number or address May be disoriented to time/ place
Moderate	4. Decreased capacity to engage in complex activities of daily living (e.g. preparing meals, ordering from a menu) 5. Needs help to select appropriate clothing and reminders to bath properly 6A. Difficulty dressing 6B. Requires assistance bathing 6C. Difficulty toileting 6D. Urinary incontinence 6E. Fecal incontinence	Will remember own name but forgets the name of caregiver spouse Able to recall events in the past but may have difficulty remembering more recent experiences Disoriented to time and place May be unable to count forward or backward from ten
Advanced	7A. Vocabulary limited to 1 to 5 words 7B. No vocabulary 7C. No ambulatory skills 7D. No ability to control head, neck and trunk 7E. No ability to smile 7F. Limited awareness of environment	May not have verbal communication abilities or psychomotor skills

Note. Adapted from: Reisberg, 1984; Reisberg, 1986; Reisberg, 1988; Reisberg & Franssen, 1999.

Overall, it would be helpful to gain precise knowledge regarding strategies for changing behaviour across the span of the disease, in order to facilitate the development of stage-specific interventions that would support both a PWD and their family caregiver during mealtime, whilst living in the community. The next chapter provides a summary of relevant literature to support this inquiry.

Chapter Two: Review of the Literature

Chapter two provides a review of the available literature on the mealtime experiences of a person with dementia (PWD) and their caregiver. It also includes a comprehensive synthesis of the single published study related to the mealtime experience of PWDs and their community caregivers.

To gain an understanding of, as well as justify the need to investigate the mealtime experience and strategies of PWDs and their caregivers living in the community, a search for electronic information published between 1985- 2007 was performed. The following search words: mealtime, eating, dementia, Alzheimer's disease (AD), community, and qualitative and quantitative studies, were entered into the CINAHL and PROQUEST databases. Combinations of the search terms yielded one article that specifically focused on exploring the experience of mealtimes in the community (Keller, Cook & Edwards, 2007), signifying the lack of current literature about mealtime in the community for PWDs and their primary caregivers. In fact, Keller et al. suggested that their work was the first known study to explore the meaning of mealtimes for the caregiver living in the community rather than solicit information about the challenges that they faced. At this point, hand searches of the reference lists in journal articles and the table of contents of key dementia journals were performed, which yielded no additional results. In order to gain an understanding of the challenges and successes related to the mealtime experiences of PWDs and caregivers, additional literature was identified that was not specific to this phenomenon. This literature was reviewed according to the food and mealtime experience for both the PWD and caregiver, and followed by a detailed description of the single published study that was specific to the purpose of the secondary analysis.

Food and Mealtime for the PWD

Due to the symptoms and manifestations of dementia stated in the background chapter, it is understandable that mealtime may present difficulty for a PWD. One of the most significant issues for PWDs at mealtime is the risk of reduced food intake resulting in a poor nutritional status (Durnbaugh, Haley & Roberts, 1993). Weight loss is indicative of a reduced food intake and malnutrition, which is often a key indicator in the diagnosis of dementia in the elderly (Barrett-Conner, Edelstein, CoreyBloom & Wiederholt, 1996). In fact, Donini, DeFelice and Cannella (2007) state that weight loss and malnutrition serve as a predictor of mortality in people with Alzheimer's disease, especially if the weight loss is more than 5%. Malnutrition also places PWDs at risk for respiratory disturbances, decreased cognition and increased delirium (Boczko, 2004). It also places previously hospitalized individuals at greater risk for admission to an institution, such as a long-term care home (Andrieu, Reynish, Nourashemi, Ousset & Grandjean et al., 2001). In addition, malnutrition is widespread among older PWDs living in the community (Andrieu, et al.). Therefore, it is relevant to investigate the mealtime experiences for PWDs and their caregivers as the disease progresses in order to understand the strategies used to prevent and cope with possible malnutrition at later stages of the disease trajectory.

Mealtime may present special challenges for PWDs and their caregiver, due to the physical and behavioural manifestations of the disease. There are many physical factors that can lead to disappointment and frustration for a PWD (Kellaheer, 2000), thus negatively affecting their caregiver who may be heavily involved with mealtime preparation and delivery. Physical limitations may prevent the intake of food and include but are not limited to the inability to recognize appropriate food substances, manipulate utensils, perceive hunger or thirst, open the mouth, chew and swallow (Keene & Hope, 1996; Manthorpe & Watson, 2003; Volicer, 2005;

Volicer, Seltzer, Rheaume, Karner & Glennon et al., 1989; Watson, 1997). Choking on food is another factor that prevents adequate intake for PWDs and represents a significant fear for families (Volicer et al.).

Along with the physical factors that progressively deteriorate during the dementia illness trajectory, behavioural issues can also hinder nutritional status in PWDs. Rivière, Gillette-Guyonnet, Nourhashemi and Vellas (1999) suggest that even when PWDs are completely assisted at mealtime, they may respond to offered food in challenging ways. For example, refusing food by preventing it from entering their mouth, and refusing to swallow or letting the food fall from their mouth (Watson, 1997). Wandering away from the meal is another significant behaviour which prevents PWDs from obtaining enough nutrients to maintain a healthy nutritional status or to fully enjoy the social aspects of mealtimes (Beattie, 2002; Klein, Steinberg, Galik, Steele, Sheppard & Marie, et al., 1999). Overall, the literature showed that the changes in behaviour from the pre-morbid state to advancing dementia are significant and progressive.

Food and Mealtime for the Caregiver

Providing meals and engaging in mealtime lends itself to caregiver burden for family members living in the community (Rivière, Gillette-Guyonnet, Andrieu, Nourhashemi, Lauque & Cantet et al., 2002). The aforementioned mealtime behaviours and physical limitations of PWDs may contribute to increasing caregiver concerns over the difficulties faced at mealtime (Manthorpe & Watson, 2003). In addition, Donini et al. (2007) suggest that nutrition often becomes the main focus of the mealtime, shifting the focus away from socializing and making a connection. It is reasonable that the stresses caused from providing and delivering a meal to a PWD may lead family caregivers to develop and utilize necessary strategies to help them cope.

In addition, the opposite may prove to be true, where situational stress renders the dyad unable to identify any strategies. Therefore, an in-depth analysis is needed to discover the progressive strategies used by dyads of PWDs and their spousal or adult child caregivers in the community, during mealtime throughout the dementia illness trajectory. In addition, if strategies can be identified, they may serve as useful suggestions to other dyads living in the community.

Food and Mealtime in Long Term Care

The literature search also demonstrated that previous researchers have focused their efforts on investigating mealtime in the context of long-term care homes and describing the relationship of the resident with the staff with regard to feeding behaviours, strategies and interventions (Amella, 2002; Chang & Lin, 2002; Kayser-Jones, 1996; Littlewood, 1994; Littlewood, 1997). This literature suggests that health care professionals need to move away from “task” orientation during mealtime in order to establish and maintain meaningful relationships with residents with dementia. Perivolaris, LeClerc, Wilkinson and Buchanan (2006) suggest that institutional settings oftentimes do not create a resident-focused dining experience. Perivolaris et al. found that providing an environment conducive to enabling a PWD during mealtime can enhance their dining experience. Strategies such as inviting the residents to dine together rather than being isolated in their or serving a “family style” meal where they can select their own portion of food. Therefore, these findings from the long-term care home setting may lend themselves to developing and implementing strategies to cope during mealtime between the PWD and his or her caregiver in the community.

Single Published Study Related to the Secondary Analysis

The single community study identified, *Mealtime experiences of families with dementia*, (Keller, Edward & Cook, 2007) described how family caregivers of PWDs experience mealtime.

This study served as the foundation for the *Eating together in families with dementia: A longitudinal analysis* study on which the secondary analysis was based. Keller et al.'s qualitative study, revealed the mealtime perspective of 23 caregivers of PWDs living in the community in South Central Ontario. Semi-structured interviews were conducted to inquire about the "mealtime and eating concerns of caregivers, identification of typical patterns of eating and changes in eating conduct, and caregiver strategies for coping with such changes" (Keller et al., p. 432). The researchers used NVivo to collate the interview data which was collected between June 2002 and January 2003 (Keller et al.). The participants in this study identified 55 'eating conduct changes' related to how the PWDs consumed their meal. These were identified in twelve main categories of 'eating conduct changes' which included: eating styles, difficulty self-feeding, assistance feeding, etiquette, resistive/disruptive behaviour, eating out, impaired memory and judgment, cooking difficulty, agnosia, change in food/taste preferences, rituals/routines and other. Keller et al. also acknowledged 76 potential 'adaptations made by the family' to cope with the changes to eating conduct.

Keller et al. (2007) also identified six general concepts that highlighted how caregivers needed to adapt to the changing needs of their PWD during the mealtime experience. Keller et al. presented the theme 'eating together is social,' and explained that caregivers described mealtimes as a 'routine social activity' and an occasion to converse and connect with the PWD. 'The need to simplify', was another general theme where caregivers described strategies that they used to reduce strain and yet still promote the independence of the PWD (Keller et al.). The third theme highlighted by Keller et al. was 'feed and please,' where caregivers explicated their frustrations with trying to provide nourishing yet pleasurable food to the PWD. The fourth theme explained by Keller et al. was 'throwing in the dish towel,' in which caregivers expressed that

they felt challenges and stresses during the mealtime experience. 'The shrinking plate was the fifth theme that was detailed in Keller et al.'s study. This theme highlighted that the caregivers felt that they were limited in the types and portions that they could provide to the PWD. The final theme identified by Keller et al. was 'stepping in' in which caregivers explained the strategies that they used to assist in making mealtimes more enjoyable for both themselves and the PWD.

Overall, Keller et al. (2007) concluded that mealtimes were not simply about eating but rather a time for pleasure and connection between the caregiver and PWD. Indeed, these caregivers experienced challenges during the mealtime process which were captured in the 'feed and please,' 'throwing in the dish towel' and 'the shrinking plate' themes. However, caregivers also expressed that they valued mealtime because of the opportunity that it presented for the "physical, social and emotional connection" that was established when they ate together with the PWD (Keller et al., p. 437).

While the work of Keller et al. (2007) provided valuable insights into the mealtime experience, there were gaps in this study which supported the need for further analysis and inquiry. First, the authors did not describe the level of dementia that the participants were experiencing, and therefore, it was not possible to identify stage-specific experiences or strategies of caregivers for PWDs. Discovering and subsequently communicating the strategies for coping during mealtime according to the stages of dementia is a critical addition to the literature. To date, interventions according to the staging of dementia have been identified in the domains of leisure activities and communication (Nissenboim & Vroman, 1998; Rau, 1993).

Another gap in the foundation study by Keller et al. (2007) was that while the perspective of the caregiver was solicited, that of the PWD was not. Therefore, the event of mealtime for

perhaps the most significant individual experiencing this phenomenon has yet to be explored. It is essential that further research includes the viewpoints of both the caregiver and the PWD. In addition, the foundational study offered mealtime strategies labeled in the article as 'adaptations trialed by the family' (Keller et al., p. 433). These strategies were generated by the families through trial and error in order to help deal with the dementia behaviours at mealtime. However, the strategies used with respect to specific role relationships were not explicated in this study, therefore it justified the purpose of the study to compare and contrast the roles. In fact, Gordon and Perrone (2004) identified that there is a difference in perceptions of caregiver burden, where spousal caregivers report a greater level of depression and stress when compared to adult child caregivers with a disabled parent. It is therefore important to conduct further research to discover the strategies that are specific to the caregivers in spousal relationships compared to those who are children.

While this foundational study elucidated the general experience of mealtime for families living with dementia, a more in-depth analysis was warranted to further explore some of the gaps identified in Keller et al.'s (2007) work. Indeed, Keller recruited two additional expert researchers in dementia care (Dupuis and Schindel Martin) to join an interdisciplinary team to further expand this foundational study. The goal of the research team was to design and implement a study that would become the next phase of a program of research, striving to uncover further descriptions of mealtime experiences in the community, and address some of the gaps of this foundational study.

Data from the second study (Keller, Dupuis and Schindel Martin) served to inform this in-depth secondary analysis which sought to identify and elucidate the mealtime strategies that were specific to the stage that the PWD and their caregiver were experiencing in the community.

It is evident that the aforementioned physical and behavioural limitations that can be present during mealtime may alter the mealtime experience for both the PWD and their caregiver in terms of feeding pragmatics and the social context in which the meal is consumed (Rivière, 2002). It is reasonable to infer that dyads consisting of a PWD and their caregiver living in the community will need to develop and use strategies to cope with the anticipated physical and behavioural issues.

Overall, this chapter addressed the process I engaged in for the review of the literature and then the areas for further research that were identified through reviewing the foundational work of Keller et al. (2007). The next chapter will describe the methods used to conduct the secondary analysis.

Chapter Three: Methods

Chapter three will explain the methods I used to conduct the secondary analysis. The following topics are discussed in this chapter include: my underlying assumptions, descriptions of the primary study on which the secondary analysis was based, purpose, research questions, guiding theoretical frameworks, study design, setting, description of the sample, data collection, methods of data analysis and interpretation, rigor, ethics, and limitations of the secondary analysis.

Underlying Assumptions

It is important to first explore my assumptions related to the mealtime experience for a person with dementia (PWD) and their caregiver, before embarking on the description of the process I engaged in to conduct the secondary analysis. Creswell (1998) supports that researchers need to acknowledge their preconceived notions of a phenomenon before engaging in analysis. In recent years, I have enjoyed working as both a student nurse and subsequently, as a Registered Nurse with various geriatric populations. During this time, I worked in a continuing care setting, where I was able to care for PWDs and their family members on an ongoing basis. My time spent with PWDs has led me to understand that they are unique individuals, who live in the moment. Caring for this population has also allowed me to engage in the mealtime event of feeding people with advanced dementia.

As I reflected upon the experience of feeding a PWD exhibiting behaviours such as refusing food or choking, I noticed that I had to resist being "task oriented" as described in the literature review. Also, at times, I had what I describe as a numb sensation, where I did not gain a sense of mutual appreciation or engagement during mealtime with a PWD. During these feeding experiences, I was primarily focused on the risks of malnutrition, as most of the time

they had to be coaxed to eat, worrying me that they were not ingesting adequate calories to maintain a stable weight. Therefore, when I began engaging in the secondary analysis I held the assumption that caring for a PWD in the later stages required much more effort to engage in both the practical aspect of feeding as well as the social aspects of the mealtime. My experience has led me to believe that caring for PWDs during mealtime in the late stages means planning and strategizing how to get them to ingest food, as well as having patience and understanding.

In contrast, I found that for residents who were only slightly to moderately affected by dementia, I was able to focus on more of the social aspects of the meal such as setting up their food tray to their exacting specifications or engaging in leisurely conversation. As I reflected on these occurrences, I noticed I gained pleasure from the mealtime experience with these residents as they were able to reciprocate conversation and express interest in the meal. Therefore, I began this study with the assumption that social engagement is a critical strategy that might be mentioned by the participants. Overall, I believed that PWDs in the early to middle stages were more able to participate in mealtimes because they generally required minimal encouragement to eat as well as actively engage in conversation.

In addition to my own mealtime experiences in an institutional setting, I was able to observe the experiences of other health care providers (HCP). HCP is used in this context as an umbrella term to describe Registered Nurses, Registered Practical Nurses and Health Care Aids. Some HCP exhibited exemplary care and patience while feeding and assisting PWDs during mealtime. However, many demonstrated a task oriented approach. HCPs could become frustrated and cease to feed a PWD as soon as they showed any type of challenge such as letting food fall from their mouth or slowing in their pace of chewing and swallowing. Often times, HCPs would also watch television or talk to another staff member while feeding the resident, which I

interpreted as completely disengaging from the PWD during the mealtime. After considering these observations, I believed that there was an opportunity to socially engage with the PWD; however the time and inclination on the part of the HCPs must be present.

Along with my clinical practice as well as observing other HCPs, I was also informed of the mealtime experience by family members who regularly fed their PWD. In the case of two spouses of PWDs, I found their approaches differed as they used a softer tone of voice and lengthened the time they spent feeding their spouse as compared to myself and other HCPs. I felt that this gave them a sense of involvement in their spouses' care and that they viewed mealtime as an opportunity to enjoy their company. These two spousal couples demonstrated to me that mealtime is not just about simply nourishing the PWD in the physical sense but rather spending time together to feed the soul. Overall, in the context of a health care institution, I felt that mealtime was one of the only opportunities that PWDs and HCPs had with each other that was socially meaningful. I thought that mealtime served as a more natural opportunity to converse and be with each other as opposed to bathing or toileting.

Description of Primary Study on Which the Secondary Analysis is Based

This secondary analysis was based on the data obtained from the *Eating together in families with dementia: A longitudinal analysis* study, in progress by Heather Keller, PhD., Sherry Dupuis, PhD. and Lori Schindel Martin, PhD. The investigators of the primary study identified three general research questions with the objective of understanding the mealtime experiences of the participants. These were:

(1) What are the experiences and meanings of food and mealtimes for persons with dementia and their primary family caregivers?

(2) How do the experiences and meanings of food and mealtimes impact the caregiver/care recipient relationship and family unit in the dementia context?

(3) How do the experiences and meanings of food and mealtimes change over time?

(Keller, Dupuis & Schindel Martin, 2004)

After obtaining ethics approval (See Appendix A), the investigators of the *Eating together ...* study, recruited dyads comprised of PWDs and either their adult child (AC) or spousal (S) caregiver from a variety of places in South Central Ontario. These included: Alzheimer's Society chapters, early stage support groups and assessment clinics (Keller, Dupuis & Schindel Martin, 2004). In the primary study, the investigators selected their sample by using four criteria, including:

1) both the person with dementia and their caregiver must be willing to participate in the project; (2) the person with dementia must be in the early or mid stages of dementia and be able to communicate his/her experiences around food and mealtimes; (3) the partner in care must be a close family member of the person with dementia (e.g., spouse, adult child); and (4) the person with dementia and their partner in care must reside in the same household or community" (Keller, Dupuis, Schindel Martin, 2004).

These general criteria formed the initial sample of 27 dyads that consented to take part in three sets of individual and joint interviews, dispersed over three years (See Appendix B & C) (Keller, Dupuis & Schindel Martin, 2004). While it was the original intention of the primary research team to sample dyads experiencing the early to middle stages of dementia, a number of the participant dyads were at a more advanced stage. The interviews were approximately 60 to 90 minutes in length, audio taped, and then transcribed verbatim by a research coordinator. The study is in its third year, with participants who are actively engaged in the interview process.

Interviewers also wrote personal reflections and created dyad composites which gave a brief but detailed account of the dyads' mealtime experiences.

In addition, study participants attended a gathering held in April 2007 to hear about the preliminary results from year one data analysis and contributed to the refinement of the evolving framework. Using the grounded theory, constant comparative analysis as described by Charmaz (2006), three main themes evolved after analyzing two sets of interviews: Evolving Life, Being Connected and Preserving Identity (Keller, Dupuis & Schindel Martin, 2007).

Purpose of the Secondary Analysis

The purpose of the secondary analysis was to describe mealtime strategies used by dyads to cope with dementia behaviour at different stages of the progressive. These dyads consisted of a PWD and either their S or AC caregivers within the community focusing on a sub-sample of ten dyads from the original 27. Overall, the results of the secondary analysis have been used to create a coding framework which organizes useful categories of strategies to cope with progressive dementia behaviours during mealtime and to ultimately advance knowledge around mealtimes in community dwelling families. The coding framework may also serve to inform the data analysis in the ongoing research in the primary data set by the research team.

Research Question

What mealtime strategies have dyads consisting of a person with advancing dementia and their spousal or adult child caregiver living in the community developed to cope with dementia behaviours as the disease progresses?

Sub-questions

How do the strategies relate to the distinct stages of the disease and how do these strategies compare?

How do the strategies and the reasons behind their use compare between the dyads of a person with advancing dementia and their spousal caregiver and the dyads of a person with advancing dementia and their adult child caregiver?

Guiding Theoretical Frameworks

Personhood. Two theoretical frameworks were used to guide the process of the study design development. The personhood movement, the development of which is often accredited to Tom Kitwood (1997), served as the main guiding theory in this secondary analysis. This movement is grounded in tenets associated with social interactionism, wherein the person views oneself in a social context (Kitwood, 1997). Of critical importance to this area of research that Kitwood proposed is that "personhood emerges in a social context" (Kitwood & Bredin, 1992, pg. 275). This notion suggests that the social context of the mealtime experience has potential impact on personhood. Kitwood (1997) adds that personhood "is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 9). Mealtime interactions may provide an important vehicle through which this fundamental trust and respect is realized.

It has already been established by Cotrell and Schultz (1993) that the majority of Alzheimer's disease (AD) research does not recognize the PWD as someone who is able to contribute to the understanding of the disease. Warchol (2006) interprets Kitwood's definition of personhood to mean that a person is more than his/her cognitive ability and argues that their feelings, actions and identity are inextricably linked. The personhood movement recognizes PWDs as capable human beings in direct contrast to Brooker's (2003) observation that society as a whole does not value them. As a result, those with cognitive impairments often have little say in their health care and interventions (Brooker). The use of the personhood movement in the

secondary analysis was used a substantive lens in which the data was viewed. Therefore, the study built on this gap in the literature by giving PWDs a voice with respect to the specific strategies used that influence mealtime experiences.

Attachment. In addition to the personhood movement, the concept of attachment in older adults also helped to guide the secondary analysis. Originally, the concept of attachment came from Bowlby's work with mothers and their children published in *Attachment and loss (Vol. I, II & III)* (Bowlby, 1969; 1973, 1980). Through the influence of psychoanalysis (Freud) as well as ethology and control theory, Bowlby (1980) was able to define the concept of attachment as "any behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual" (p.38). Thus far, the concept of attachment in nursing inquiry and theory development has almost exclusively centered on the maternal- fetal or parental- fetal relationship (e.g, Gaffney, 1986; Mercer et al., 1988 as cited in Cookman, 2005). However, its application as a framework for research aiming to understand the experience of older adults has received little attention. This is interesting, given that Bowlby has indicated that attachment behaviour is apparent throughout the lifespan (Bowlby, 1980; Wright, Hickey, Buckwalter & Clipp, 1995). In light of the limited research of attachment and yet its presence in later life, Cookman (2005) presented a concept of attachment specific to the older adult population as follows:

Attachment refers to feelings of safety and security afforded by proximity to attachment figures in response to reliable clues to danger, challenge or conflict. To the extent that the person is confident in attaining these feelings when needed, they can more fully interact with the environment, mobilize developmental resources, and address developmental tasks. (p. 533)

The defining attributes presented in this concept were proximity keeping, secure base effect and separation protest (Cookman, 2005). Two of the defining attributes of the concept of attachment, specifically, secure base effect and proximity keeping, were used to understand the mealtime experience of PWDs and their caregivers. Secure base effect presents itself during challenging and/or fear provoking situations (antecedents of attachment behaviour) where a retreat to the attachment figure will provide a safe haven or return to a "secure base" (Bowlby as cited in Cookman, 2005, p. 530). Proximity keeping is acted out when the individual seeks to remain in close proximity to the symbol or person who represents that secure base (Ainsworth, as cited in Cookman, 2005, p. 532). In fact, Wright et al. (1995) assert that attachment behaviour is evidenced in the care that a child gives to a parent who is chronically ill with AD. Caregiving that involves the preparation and sharing of food during mealtimes serves as an opportunity to fulfill both of these defining attributes of the concept of attachment as it applies to later life. Therefore, attachment provided an additional lens through which I could understand the strategies that were selected by dyads during the mealtime experience.

Study Design

A retrospective interpretation approach as described by Thorne, (1996) was used to analyze the data, due to its content from the primary study and the purpose of the secondary analysis. According to Thorne, retrospective interpretation involves the investigator accessing data in a primary study, in order to explore new questions that were not fully answered. Since this secondary analysis sought to provide an in-depth analysis of existing data to identify strategies used to cope during mealtime for community dwelling PWDs and their caregivers, the retrospective interpretation as described by Thorne was supported. In addition, Szabo and Strang (1997) stress the importance of the fit between the data from the primary study and the research

question guiding the secondary analysis. The first and third objectives in the primary study indicated that the data set would support the research questions in the secondary analysis because the mealtime experiences were captured across time, as the disease potentially progressed. Therefore, it was reasonable to assume that the previously collected data was congruent with the research question, and therefore a secondary analysis was appropriate.

It is important to note that the retrospective interpretation approach is gaining support in qualitative research (Boydell, Gladstone & Volpe, 2006). It is advantageous to make use of costly and valuable human data (Thorne, 1996) such as the data collected in the funded, primary longitudinal study (Keller, Dupuis & Schindel Martin). Therefore, taking a secondary analysis approach to the study was economically beneficial. In addition, as suggested in Szabo and Strang (1997) secondary analysis as a method ensures that 'sensitive' populations of study participants, such as PWDs and their caregivers are not overburdened with the research process. Since the secondary analysis did not require additional participation from the original study participants, the PWDs' time and their caregivers' capacity to care for their family member were not interrupted.

Sample. The study was a secondary analysis, and therefore, no human participants were sampled. Thus, the data was gathered from the transcripts of the interviews, dyad composites and reflections obtained from the dyads consisting of a PWD and the AC and S caregivers in the primary study. This secondary analysis employed purposive sampling, and originally it was decided that between six and nine dyads from year one and/or two of the primary study would be selected for analysis. It was decided through a discussion with my thesis supervisor that this sample size would provide sufficient scope into the phenomenon. Consequently, three dyads were selected to represent the early stage experience, three dyads for the middle and four dyads

for the late stages. According to Speziale and Carpenter (2007) purposive sampling is necessary in qualitative research in order to obtain a sample of participants whom have had first hand experience of the phenomena being investigated. The secondary analysis employed a new inclusion criterion in order to obtain a sample that was amenable to the research purpose and question. Specifically, in at least two or three dyads, the PWD would be considered to have a more advanced/late dementia diagnosis according to Reisberg's (1988) Functional Assessment Staging Tool. This tool was selected because it was already used as a demographic descriptor in the primary study and would ease the sample selection process. As stated earlier, the primary research team sampled dyads with more advanced dementia, and therefore I was able to make use of the existing dyad pool.

Setting. The participants who were recruited for the primary study resided in South Central Ontario. It is important to note that all PWDs were living in the community setting and that their primary caregiver was either living in the same community or dwelling. The interviews from which the transcripts were derived were conducted in the natural setting of the PWD's home. While I had not been in the homes of the selected participants, the reflections and dyad composites captured by the primary interviewers were read, in order to uncover some of the context of the interviews. Some of the interpretations of the contextual factors included: the perceived relationship between the members of the dyad, the personalities of the participants, their home environment, their comfort level and physical mannerisms. Reading the reflections and dyad composites written by the primary interviewers as well as discussions I had with my thesis supervisor allowed me to believe that I adequately understood these contextual factors, although these understandings could never be as rich as had I been present or participated in the interview itself.

Data Collection. As this study was based on a secondary analysis design, the data was already obtained from the PWD and their AC or S caregiver by the primary investigators. The interviews were approximately 60 to 90 minutes in length, audio taped, and then transcribed verbatim by a research coordinator. The verbatim transcripts, reflections and composites were accessed through my thesis supervisor, an investigator in the primary study.

Data Analysis. The following provides the step by step process that I engaged in to analyze the data using a thematic content analysis approach. Data analysis began when I selected dyads from which to gain access to their interview transcripts from the primary study. The interviews from these dyads were selected according to the inclusion criteria listed above as well as discussions with my thesis supervisor. According to Granheim and Lundman (2004), when doing qualitative content analysis the researcher needs to select the unit of analysis to be analyzed. Granheim and Lundman suggest that the most appropriate unit of analysis is a whole interview; therefore the verbatim transcripts were used in the secondary analysis. In addition, the reflections and dyad composites which corresponded with the interview transcripts in the primary study were read to gain a better sense of the context of the interview experience.

As previously discussed, there were a total of 27 possible caregiver dyads from which to select the sample for the secondary analysis. Being aware of the inclusion criteria, my thesis supervisor consulted with the co-investigators of the primary study in order to collaboratively suggest dyads that were complimentary to my research questions. A total of eleven dyads were suggested by the primary research team, including: four AC and seven S caregiver dyads from the primary data set. One AC and three S caregiver dyads experiencing early stage dementia; one AC and two S caregiver dyads experiencing middle stage dementia; and two AC and two S caregiver dyads experiencing late stage dementia were included in the suggested sub-sample.

The stage of dementia was determined by the interviewer in the primary study. After consulting with my thesis supervisor, I received brief, one to two paged, dyad composite descriptions of the suggested dyads to be included in the secondary analysis sample.

I read through hardcopies of the dyad composites in ascending order of the identifying numbers they were assigned, as opposed to grouping them according to the stage of dementia experienced by the dyad or the type of caregiver. I read the composites twice, before deciding that I could eliminate one of the early stage S caregiver dyads. Given my previous assumption that people experiencing early stage dementia did not require as much planning and strategizing during mealtime when compared to those in the later stages, I felt confident in purging this dyad from the sub-sample set. I discussed this decision with my supervisor who concurred that I was not likely to uncover any additional mealtime strategies by including that specific dyad, based on her knowledge of the full transcript set. Therefore, I was left with ten dyads to analyze, including four AC and six S caregiver dyads which made up the sub-sample. These included: three early, three middle and four late stage dyads.

Of the dyads selected, five different people conducted the interviews. The dyads also varied in the amount of information available, including the length and depth of the interviewers' dyad composites and reflections, as well as the number and types of interviews that the dyads participated in. For example, dyad 1 only participated in the joint interview during the first year of data collection, while other dyads completed both individual and joint interviews during both years of data collection. Table 2 provides a summary of the available transcripts according to the dyads' stage and numeric identifier; interview type and date conducted; and stage of the study.

After the dyads were selected for analysis, the second step involved reading through and analyzing the transcripts. Creswell (1998) suggests that some form of coding and categorizing of

data exists in all qualitative research analysis. However, since qualitative secondary analysis is not well described in the literature (Szabo & Strang, 1997), a standard for analyzing this type of data is not available. Therefore, a thematic content analysis approach as described by Burnard (1991) was selected as a method of analysis because of its underpinnings and assumptions about the data being analyzed. Burnard developed fourteen stages of thematic content analysis through the influence of the work of Glaser and Strauss (1967) and their approach to grounded theory analysis. Since Glaser and Strauss (1967) are well recognized and respected in their approach to qualitative research (Charmaz, 2006), the underpinnings for the stages of analysis were supported. Most significant was Burnard's stated criteria that the data being analyzed must be derived from semi-structured, open-ended and completely transcribed interviews. Since the data from the primary study met these criteria, this thematic content analysis approach to data analysis was appropriate.

Table 2
Available Transcripts for Analysis

Stage of Dementia	Dyad	Year One Dyad Interview	Year One Caregiver Interview	Year One PWD Interview	Year Two Dyad Interview	Year Two Caregiver Interview	Year Two PWD Interview
Late	1	✓ October 2005	NA	NA	NA	NA	NA
Middle	4	✓ December 2005	✓ December 2005	✓ December 2005	✓ November 2006	✓ November 2006	✓ November 2006
Early	5	✓ December 2005	✓ January 2006	✓ December 2005	✓ December 2006	✓ December 2006	✓ December 2006
Early	6	✓ January 2006	✓ January 2006	✓ January 2006	✓ January 2007	✓ January 2007	✓ January 2007
Early	12	✓ February 2006	✓ March 2006	✓ March 2006	✓ February 2007	✓ March 2007	✓ March 2007
Late	13	✓ February 2006	✓ March 2006	✓ March 2006	NA	✓ February 2007	✓ February 2007

Stage of Dementia	Dyad	Year One Dyad Interview	Year One Caregiver Interview	Year One PWD Interview	Year Two Dyad Interview	Year Two Caregiver Interview	Year Two PWD Interview
Late	17	✓ May 2006	✓ May 2006	✓ May 2006	NA	NA	NA
Middle	19	✓ May 2006	✓ June 2007	✓ June 2007	✓ June 2007	✓ June 2007	✓ June 2007
Late	22	✓ July 2006	✓ July 2006	✓ July 2006	NA	NA	NA
Middle	23	✓ July 2006	✓ July 2006	✓ July 2006	✓ April 2007	✓ May 2007	✓ April 2007

Note. NA indicates that the interview was not done; ✓ indicates that the interview was available,

Month/Year indicates the month and year that the interview was conducted.

In order to follow through with analyzing the data, the first ten of the fourteen stages of thematic content analysis as described by Burnard (1991) were followed. These stages specifically focused on the handling of data to be analyzed. Table 3 provides a summary of Burnard's stages of analysis and the adaptations that were made in the secondary analysis.

Table 3

Burnard's Stages of Thematic Content Analysis

Stage	Description	Secondary Study Application
One	Note and memo writing	Read over field notes and memos
Two	Read over entire transcript set	Read over entire transcript set
Three	Open coding	Identified and labeled all codes in the data
Four	Axial Coding	Relating the codes to each other and collapsing categories
Five	Revise new list of categories through collapsing categories	Relating the codes to each other and collapsing categories
Six	Two colleagues to generate separate lists of categories and agree on final list of categories	Discussion of categories with thesis supervisor and meeting with primary research team
Seven	Transcripts re-read with final list of categories	Selected transcripts re-read to ensure categories were congruent
Eight	Individual categories are colour coded	Method adapted by creating word documents according to code and categories
Nine	Codes in the transcript are colour highlighted according to category	Method adapted by creating word documents according to code and categories
Ten	Each colour code is cut and copied into a word document specific to its category	Codes were copied into a word document specific to the dementia stage and categories

Note. Adapted from Burnard, 1991.

According to Burnard (1991), the first stage of thematic content analysis involves recording notes after each interview which focuses on the topics discussed. Since I was not involved in the primary study interviews, the reflections and dyad composites written by the primary interviewers were read through to gain a sense of the important features and content of the interview. Much like the dyad composites, I read the interview transcripts in ascending order, according to their numeric identity code assigned during the primary study. Since I wanted to gain a sense of the mealtime experience for all dyads experiencing dementia, I used this method to ensure that I would be 'mixing up' the dyad type and stage of dementia. I also felt that this was the best method for me to follow so that I would not be tempted to begin coding the data according to stage or caregiver type in the early stages of data analysis. Creswell (1998) advocates to researchers the importance of gaining a sense of the whole set of the data before coding. I made electronic memos and notes to myself as I read through the interview transcripts and interviewer reflections and dyad composites noting the points of interest, similarities and quandaries.

The next stage of the analysis process involved reading through the entire transcript set (unit of analysis) while noting general themes presented in the transcript. Again, Creswell (1998) supports this initial step in data analysis because it allows the reader to become immersed in the data and become more aware of the participant's 'life world' (Burnard, 1991).

After the two preliminary stages of the data analysis as explained by Burnard (1991), a process of open coding was initiated in the third stage. In this stage the transcript is read through and codes are used to describe and label all codes in the data (Creswell, 1998). Therefore, after having completed reading the entire data set and making notes accordingly, I consulted with my thesis supervisor to plan the next steps. We mutually decided that I should begin by analyzing

and coding the dyads experiencing late stage dementia. With my thesis supervisor having intimate knowledge of the data set, she encouraged these interviews as a starting point because she felt that I would be able to recognize the most mealtime strategies associated with late stage dementia based on my clinical expertise. I willingly agreed, as I was initially uncertain that I would gain as much from the middle, and especially early stage dyads. Therefore, like my previous experiences with the data, I read and coded the interview transcripts for dyads experiencing late stage dementia according to the ascending order of their numeric codes. I subsequently repeated this process with middle and early stage dyads. This coding exercise was done electronically through a word document program.

After the codes and resulting categories are generated, Burnard (1991) explains that categories can be collapsed to avoid redundancy. Therefore, during the fourth stage, any codes that were deemed to essentially have the same meaning or appear to be related were collapsed into categories known as axial coding (Creswell, 1998). I engaged in this process by looking for repetitive quotes, words or ideas within each of the transcripts and then expanded this idea by grouping and collapsing the codes according to stages of dementia. I felt that I needed to do this in order to gain a sense of which codes were relevant to each specific stage of dementia. I did not believe that it was reasonable to group the codes according to caregiver type, at this stage.

Next, Burnard (1991) states that a new list of revised and collapsed categories is to be created and further scrutinized for repetitious categories in the fifth stage. For this step, I gained the assistance of my thesis supervisor. After completing my initial open and axial coding of the late stage dyads, we discussed my preliminary codes and emerging categories. I used this opportunity as a 'member check' as my thesis supervisor was knowledgeable about the categories from the emerging theory in the primary study. While the term 'member check' generally refers to the

researcher validating their emerging findings with the study participants (Creswell, 1998), I have used it in the context of this project as the process through which the secondary analyst engages in dialogue with a member of the primary research team to confirm that the findings are grounded in the data. While discussing my progress, we decided that I would make stylistic changes, and focus more on determining additional social strategies associated with mealtimes. After this, I engaged in the same process as just described for the middle and early stage interview transcripts. Overall, these meetings would prove to serve as Burnard’s sixth subsequent step that provided an opportunity for consensus building.

While the first five stages of Burnard’s (1991) approach to thematic content analysis were accomplished without a great deal of alteration, the sixth stage required adjustment. In the sixth stage of analysis, Burnard states that the researcher should invite two additional colleagues to create a list of categories related to the data and then the three lists of categories are compared. However, this step would have been time consuming for other colleagues who were not familiar with the primary study. Therefore, in an attempt to stay true to this step, my thesis supervisor who was knowledgeable about the content of the transcripts was consulted as to the appropriateness of the list of categories, as described in the previous stage. In addition, I had the opportunity to present my preliminary findings, during a research team meeting that included the principal investigator, my thesis supervisor, and two other students attached to the project. The research team members agreed that the categories and the strategies that I presented in the coding framework were grounded in the data (See Appendix D).

After the list of categories representing the content of the transcripts is finalized in the sixth stage, Burnard (1991) explains that the transcripts need to be re-read alongside the final list of categories to ensure that all of the content is covered in the seventh step. In the study, transcripts

that provided rich data were re-read to provide a check for the final list of categories that were developed. See Table 4 for a summary of the number of times that the transcripts were read.

Table 4
Number of Times Transcripts Were Read

Dyad	Year One Dyad Interview	Year One Caregiver Interview	Year One PWD Interview	Year Two Dyad Interview	Year Two Caregiver Interview	Year Two PWD Interview
1	3	NA	NA	NA	NA	NA
4	3	3	3	3	3	3
5	3	3	3	2	2	2
6	3	3	3	3	3	3
12	3	3	3	3	3	3
13	3	3	3	NA	2	2
17	3	3	3	NA	NA	NA
19	3	3	3	3	3	3
22	3	3	3	NA	NA	NA
23	3	3	3	3	3	3

Note. Arabic number indicates the number of times that the transcript was read. NA indicates that the transcript was not available for analysis.

Once the seventh step is complete, Burnard (1991) describes the eighth stage of thematic content analysis as assigning a unique colour code to each of the established categories, for example, red will signify category X and blue will signify category Y. Subsequently, the ninth stage involves identifying the categories and their surrounding context in the transcript through

colour coding (Burnard). After each section of the transcript is colour coded according to categories in the ninth stage, each coded section of the transcript should be cut and copied into a new word document which is specific to a single category in the tenth stage (Burnard). Burnard explains that it is important to not only include the code in the highlighted section, but the sentences around the code that give it context. These stages were slightly adapted in the secondary analysis, by eliminating the need to colour code the categories, and creating word documents that listed the categories and their properties in separate word documents. Overall, the data analysis focused on the identification of categories that would qualitatively answer my research questions.

By following the stages of data analysis as described by Burnard (1991) the categories that emerged contributed to the construction of a coding framework that was presented to four members of the primary research team. Ultimately, the results of the analysis clarified the strategies used to cope with each distinct stage of dementia at mealtime for community dwelling dyads of PWDs and their caregivers. The coding framework created during the analysis process may be used by the primary research team to inform their analysis of the data in the remainder of the full sample in the primary study.

Ethics

The primary study on which the secondary analysis is based received ethics approval from the University of Guelph, the University of Waterloo, and McMaster University in 2004 (Keller, Dupuis & Schindel Martin, 2004) (See Appendix A). The Ryerson University Research Ethics Board gave approval to add my name so that I could engage in the secondary analysis as an investigator of record. In addition, before I engaged in the secondary analysis, I ensured ethical soundness to protect the participants in the primary study. Given that the study was a

secondary analysis, I was not directly in contact with the participants. The dyads consisting of a PWD and their AC or S caregivers consented to participate in the primary study and were not exposed to any physical, psychological or social risks and were compensated for the time they spent in the interviews with coupons for local restaurants and food stores. Overall, the human rights of the participants were upheld and protected in the primary study, and this continued in the secondary analysis.

Since the secondary analysis used the data obtained from the participants in the primary study, additional consents from the participants were not warranted as the research questions were congruent with the objectives of the primary study (as per Ryerson University Research Ethics Board). However, every effort was made to protect the participants' rights in the secondary analysis. The participants' right to anonymity was ensured by receiving data from the primary study that was free of any identifying information in the electronically stored or hard copies of transcripts, reflections or composites (Burns & Grove, 2005). This made certain that the participants' right to anonymity was respected. In addition, any identifying information was excluded in this document. Furthermore, all of the electronic data that was transferred from the primary study is stored on a computer, backed up by a memory key that is securely stored away from the computer. In addition, anonymity will be ensured by locking up any hard copy transcriptions, notes or reports in a protected area for a minimum of three years after completion of the secondary analysis. Also, after the secondary analysis was completed, any electronic data, such as coding records were burned on to CD, and are subsequently being kept in a locked filing cabinet for a minimum of three years. After this time, all data will be destroyed by shredding hard copies and CDs and deleting electronic documents.

Rigor

Ensuring rigor was important to make certain that the views and experiences of the participants in the study were accurately portrayed and therefore, that the conclusions I reached were supported by the data (Speziale & Carpenter, 2007). Rigor in the secondary analysis was evaluated according to the following criteria: credibility, confirmability, dependability, transferability and recurrent patterning (Leininger, 1994; Lincoln & Guba, 1985).

According to Milne and Oberle (2005), credibility is demonstrated by staying true to the intended purpose of the study, which in this case was identifying the coping strategies during mealtime, used by the dyads of PWDs and their AC or S caregivers across the stages of the disease. Since the data was analyzed solely from the participants' interview transcripts, composites and interviewer reflections, it was important to ensure that conclusions drawn about the coping strategies used by the dyads at mealtime were truthfully derived from their views and perceptions (Leininger, 1994; Milne & Oberle). Therefore, I used direct quotes from participant's interview transcripts in order to support the conclusion reached. Credibility was also facilitated by consulting the primary research team about the resulting coding framework as I did not have access to the study participants, as suggested by Thorne (1996).

In addition to credibility, two other measures of rigor were used in the secondary analysis which includes confirmability and dependability. According to Leininger (1994), confirmability means that the researcher is able to verify the conclusions drawn from the data in the study. Polit, Beck and Hungler (2001) add that "confirmability means that more than two independent researchers confirm the data's conclusions and meaning" (p. 315). Therefore, in this secondary analysis, I frequently engaged in dialogue with my thesis supervisor throughout the data analysis process. In addition, I received positive reinforcement from members of the primary research

team that my emerging coding framework and categories were grounded in the data set. Also, the concept of dependability relates to the data's consistency over time. Therefore, dependability can be demonstrated by the use of an audit trail as suggested by Lincoln and Guba (1985). Polit et al. (2001) propose keeping six classes of records including, "raw data, data reduction and analysis products, process notes, materials relating intentions and dispositions, instrument development information and data reconstruction products" (p. 216). All data, notes, drafts and journals have been stored in order to confirm the data analyzed in the secondary analysis.

The last concept of rigor as outlined by Lincoln and Guba (1985) is transferability. This concept refers to the data's ability to be transferred to other groups of people or settings (Polit et al., 2001). Lincoln and Guba propose that the researcher is responsible for providing a 'thick description' of the data in order for the reader to determine if the data is transferable to other groups or settings. Therefore, the next chapter, detailing the findings of the data analysis will provide a comprehensive description of the categories and their properties.

Finally, the concept of recurrent patterning (Leininger, 1994) was used to ensure that the single instances or outlying experiences are not overemphasized in conclusions. According to Leininger (1994; p. 106) recurrent patterning is the "repeated instances, experiences, or lifeways that tend to be patterned and recur over time." This concept is supported by the methods used in a thematic content analysis approach to data analysis, and therefore, serve to help ensure rigor. I frequently went back to the data to ensure that dyads were in fact using strategies that I had identified during analysis. I note that, because I was creating a coding framework that may inform future analysis of the entire sample in the primary study, I did not simply discard strategies and properties if they did not have recurrent mention. In addition to these standard

forms of evaluation, my thesis supervisor, whom is very well acquainted with the data as well as my thesis committee were consulted with to ensure the overall 'trustworthiness' of the data.

Study Limitations

There were two limitations in the secondary analysis that I identified before engaging in the secondary analysis which included issues with secondary analysis methodology and the sample. Limitations can be found in the research methodology of conducting a secondary analysis. In this secondary analysis, I did not have the advantage of obtaining data in the field setting, and therefore I was not aware of any contextual factors such as participants' behaviour or setting which may have influenced the data collection (Thorne, 1996). There is the possibility that the primary researchers had tacit understandings from the field setting that did not come through in their reflections or composite portraits (Thorne). Another limitation of secondary analysis that Thorne recognizes is that each of the primary investigators may have individual interpretation styles and understanding of the interview process. Thorne suggests that this may introduce bias during data collection in the primary study. The biases that may be present in the primary data may ultimately direct the conclusion made in the secondary analysis (Thorne). My thesis supervisor was repeatedly consulted as well as the interview transcripts, reflections, and dyad composites were frequently revisited in order to gain some of the tacit knowledge that ultimately helped to advance the conclusions made in the secondary analysis. A final limitation of secondary analysis as suggested by Boydell et al. (2006) and Szabo and Strang (1997) is that secondary analysis is a relatively new method of inquiry in qualitative research, and hence there is little information on which to consult in order to direct the study. However, some qualitative articles such as Oliffe and Thorne (2007) offered guidance in terms of the practicalities and methods used to conduct qualitative secondary analysis.

In addition to the general limitations of conducting a secondary analysis, the sub-sample obtained from the primary study may have limited the conclusions and implications for intervention development. According to Sink, Covinsky, Newcomer and Yaffe (2004), the prevalence of dementia is higher in the nonwhite population, yet Snyder (2001) explains that research related to AD has largely drawn on a Caucasian sample. Therefore, the results and direction for interventions likely have a cultural bias toward the Caucasian experience (Snyder). The dyads in the sub-sample from the primary study were all Caucasian and therefore, broad reaching applications to different cultural backgrounds may not be reasonably drawn.

In addition, although not a limitation, I feel that my novice status in the role as a researcher should be mentioned. More research experience could have enriched the process in terms of organization, and depth of analysis. Consequently, the findings may be limited in terms of depth and understanding. Speziale and Carpenter (2007) suggest that this limitation can be controlled by consulting with the thesis committee members who are experts in the research process or field of study. I frequently consulted with my supervisor and sought the advice of my committee throughout the entire thesis process.

Overall, this chapter has described the methods and approaches that were used to engage in the secondary analysis. The following chapter will provide a detailed description of the data from the secondary analysis.

Chapter Four: Findings

This chapter gives a concise demographic description of the person with dementia (PWD) and adult child (AC) or spousal (S) caregiver dyads that were sampled according to their stage of dementia. This chapter also describes my findings from the process of analyzing the interview transcripts, dyad composites and reflections. It is essential to include this description of the data in order to understand how I answered my research questions provided in the subsequent chapter. Therefore, this chapter presents the four categories that emerged from the data analysis. I discuss these categories that both the AC and S caregiver dyads experiencing all stages of dementia have in common, including: 1) strategies to facilitate eating; 2) strategies to promote a sense of self; 3) strategies to minimize safety risks; and 4) strategies to promote the caregiver’s sense of self. My findings are explained according to these categories using a description of the specific properties that dyads use for each progressive stage of dementia, including early, middle and later stages.

Demographic Description of Early Stage Dyads

The following is a brief demographic profile of the early stage dyads, which is also summarized in table 5.

Dyad 5 was coping with early stage dementia and consisted of a mother (PWD5) and caregiver (CG5) son living in different apartments in the same home. PWD5 had a FAST score of 3-4 as assessed during the second year interviews. PWD5 was articulate and seemed to have a high degree of knowledge and insight into her diagnosis as compared to others in the sub-sample. PWD5 felt comfortable to take the lead in the dyad interviews. Consequently, CG5 was able to ‘fill in’ the gaps and his individual strategies related to being a caregiver during mealtime.

Table 5

Early Stage Dyad Demographic Description

Demographic	Dyad 5	Dyad 6	Dyad 12
PWD Sex and Age	Female: 59	Male: 72	Male: 73
Caregiver Sex and Age	Male: 30	Female: 71	Female: 66
PWD/Caregiver Identifiers	PWD5/CG5	PWD6/PWD6	PWD12/CG12
Relationship	Mother/Son	Married	Second Marriage
FAST Score Year 1	3-4	4	3
FAST Score Year 2	4	4	3
Living Arrangement	Living in separate apartments in the same dwelling	Together	Together
Marriage Status	PWD Single CG In a relationship	Married	Relationship for 20 years

Dyad 6 was a married couple, where the husband (PWD6) had the dementia diagnosis and the wife was the primary caregiver (CG6). PWD6 was assessed as having a FAST score of 4 by the time of the second set of interviews. At the time of the interviews, the couple acknowledged that the PWD had trouble word finding and following conversation in a large group, however, he was able to participate in the interviews. It was suspected by the interviewer the PWD had not quite “accepted” the diagnosis, while the caregiver was aware the changes it was bringing to her life.

Dyad 12 consisted of a couple, a second marriage for both, who had been together for over 20 years at the time of the first year interviews. Although, the PWD (PWD12) had a FAST score of 3 at the time of the first year interviews he was already beginning to have difficulty with word finding. However, he was willing and able to participate in the interviews along with his wife (CG12). By the second year interviews the PWD experienced changes to his physical health that impacted meal choices.

Demographic Description of Middle Stage Dyads

The following is a brief demographic profile of the middle stage dyads, which is summarized in table 6.

Dyad 4 was coping with middle stage dementia. It consisted of a “loving” couple; a second marriage for both the husband (PWD4) and wife (CG4). PWD4 had a FAST score of 4 by the second set of interviews. He had an active sense of humour about him during the interviews which was complimented by the accepting nature of his wife (CG4). Both members of the dyad equally participated in the interviews and discussed their mealtime experiences and enjoyment of activities outside of the home.

Dyad 19 consisted of an elderly couple who had been married for more than 60 years at the time of the second interview. The wife was the PWD (PWD 19) and had a dementia diagnosis for five years with a FAST score of 5 by the second set of interviews. This dyad enjoyed eating together, whether it was in the home or out in the community, as a couple or with friends and family. Both the caregiver (CG19) and PWD equally but reservedly shared their mealtime experiences with the interviewer.

Dyad 23 was experiencing middle stage dementia and consisted of a mother (PWD23) and her caregiver (CG23) daughter who lived separately in the community. PWD23 had a FAST score of 4 as assessed by the interviewer by the second set of interviews. Both members of the dyad equally participated in answering questions during the interviews. During the first year of the study the dyad members lived separately, however, the caregiver was usually visiting almost daily, and they were eating dinner together frequently. By the second year, the PWD had just transitioned into an assisted living home, making this dyad unique from the rest.

Table 6
Middle Stage Dyad Demographic Description

Demographic	Dyad 4	Dyad 19	Dyad 23
PWD Sex and Age	Male: 76	Female: 86	Female: 80
Caregiver Sex and Age	Female: 65	Male: 88	Female: 47
PWD/Caregiver Identifiers	PWD4/CG4	PWD19/CG19	PWD23/CG23
Relationship	Re-Married	Married	Mother/Daughter
FAST Score Year 1	3	4	3-4
FAST Score Year 2	4	5	4 (Admitted to retirement home April 07)
Living Arrangement	Together	Together	Separate
Marriage Status	Married over 10 years	Married over 60 years	PWD Widowed CG Single

Demographic Description of Late Stage Dyads.

The following is a brief demographic profile of the late stage dyads, which is summarized in table 7.

Dyad 1 was coping with late stage dementia and consisted of a “loving elderly” couple who had been married more than 50 years at the time of the interview. In this dyad the husband (PWD1) had a FAST score of 6B. The interview transcript revealed that PWD1 conversed mostly in his native language; however his wife and primary caregiver (CG1) was able to explain and translate their mealtime experiences.

Dyad 13 consisted of a daughter (CG13) who had been caring for her mother (PWD13) with later stage dementia for about five years at the time of the first interview. PWD13 had a FAST score of 5 and was losing her ability to initiate and carry on conversation. In both sets of interviews PWD13 repeatedly talked about her past enjoyment with her occupation.

Table 7

Late Stage Dyad Demographic Description

Demographic	Dyad 1	Dyad 13	Dyad 17	Dyad 22
PWD Sex and Age	Male: 86	Female: 86	Male: 78	Female: 86
Caregiver Sex and Age	Female: 83	Female: 60	Female: 75	Male: 53
PWD/Caregiver Identifier	PWD1/CG1	PWD13/CG13	PWD17/CG17	PWD22/CG22
Relationship	Married	Mother/Daughter	Married	Mother/Son
FAST Score Year 1	6 B (Deceased 2006)	6 A-B	6A (Admitted to nursing home January 2007)	6 D-E (Admitted to nursing home February 2007)
FAST Score Year 2	NA	6 A-B	NA	NA
Living Arrangement	Living together	Living together	Living together	Living together
Marriage Status	Married 54 years	PWD Widowed CG Divorced	Married over 50 years	PWD Widowed CG Divorced

Dyad 17 consisted of a “retired couple” who had been married for more than 50 years at the time of the first interview. The husband (PWD17) was experiencing late stage dementia and had a FAST score of 6A at the time of the first year interviews. It was apparent from the interview transcripts that PWD 17 was able to converse, however, his explanations during the interview were superficial. Therefore, his wife and primary caregiver (CG17) provided more detail related to their mealtimes experiences during the interviews.

Dyad 22 consisted of a widowed mother (PWD22) who was experiencing late stage dementia. She had been living in her caregiver son’s (CG22) home for about three years at the time of the interviews. PWD22 had a FAST score of 6D to 6E, and like the PWD in Dyad 17, was only able to answer interview questions at a superficial level. Again, CG22 was responsible for describing more of the detail related to their mealtime experiences. Overall, the transcripts from these dyads served as the unit of analysis from which the following findings are based.

Strategies Used to Facilitate Eating

All dyads, both implicitly and explicitly described strategies that they used to facilitate eating both meals together as a dyad and separately as individuals. In my analysis, I defined ‘eating’ as the literal taking in of food for the PWD. My most significant finding in this category was that while all ten participant dyads expressed the strategies that they used to facilitate eating, it was apparent to me that caregiver involvement increased as the stage of dementia progressed. This finding emerged from the changes that the participants in the dyads described in the first year interviews compared to the second year interviews at the same stage, as well as the observations I made by comparing and contrasting caregiver involvement across the three stages.

The following describes the seven specific properties of the category used by participants in each stage of dementia as it progressed from early to late. The properties in this specific category are: 1) maintaining a routine; 2) simplifying; 3) preparing an appetizing meal; 4) adapting the setting; 5) eating out; 6) adapting to and accommodating the changing needs of the PWD; and 7) encouraging gently. See table 8 below for a summary of the properties’ inclusion according to dementia stage and caregiver type. It is important to note that the percentages of dyads in the sub-sample whom identified strategies are reported in the table below. The inclusion of the percentages serves to represent the number of dyads who identified with strategies, but is not an indication of their significance in the category. The percentages were included to assist clinicians to make any transferability judgments with respect to their own client population, in addition to assisting the primary research team to identify those categories that require careful consideration as the full data is analyzed.

Table 8

Coding Framework: Strategies to Facilitate Eating

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
<i>Strategies Used To Facilitate Eating</i>	Maintaining a Routine	YES	YES	YES
	10/10= 100%	S 2/2	S 2/2	S 2/2
		AC 1/1	AC 1/1	AC 2/2
	Simplifying	YES	YES	YES
	9/10= 90%	S 2/2	S 2/2	S 1/2
		A/C 1/1	AC 1/1	AC 2/2
	Adapting the Setting	YES	YES	YES
	8/10 = 80%	S 2/2	S 2/2	S 2/2
		AC 1/1	AC 1/1	AC 0/2
	Preparing an Appetizing Meal	YES	YES	YES
	8/10= 80%	S 2/2	S 2/2	S 2/2
		AC 1/1	AC 1/1	AC 0/2

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
	Eating Out	YES	YES	YES
	8/10= 80%	S 2/2	S 2/2	S 1/2
		AC 1/1	AC 1/1	AC 1/2
	Adapting to and Accommodating Changing Needs	YES	YES	YES
	7/10= 70%	S 1/2	S1/2	S 2/2
		AC 1/1	AC0/1	AC 2/2
	Gently Encouraging	NO	YES	YES
	4/10= 40%		S 1/2	S 2/2
			AC 0/1	AC1/2

Note. S indicates a spousal relationship; AC indicates an adult child relationship; X/X indicates the number of dyads which included the property

Maintaining a routine. Maintaining a routine was the most common property in the strategies that facilitated eating category. This property was identified by all ten dyads, across the three stages of dementia. Participants from both the AC and S caregiver dyads described maintaining a routine as “honouring” a specific place to eat, whether it was seated at a certain place at the kitchen table or eating in front of the television. CG22 described a typical dinner routine as:

Well, we actually, most of the time unless we've got company, I get a little table just set up sort of? right off the kitchen so that it's convenient and mom doesn't have to go too far. And she remembers where she's supposed to go.

Another common routine strategy across all stages of dementia and both dyad types was maintaining a set mealtime as described by CG19:

We usually start dinner before five o'clock. My grandmother and grandfather used to eat at five o'clock and everybody laughed at them. Now we find we're doing the same thing because we want to get done at six o'clock so we can watch the six and six-thirty news.

Maintaining a routine also involved strategies such as keeping up pre-meal rituals such as preparing appetizers, praying, physically embracing or plating the food in the kitchen. Dyads across all stages of the disease spoke about the different routines that they maintained before and since the diagnosis.

Simplifying. The next most common property was simplifying, which was identified by nine dyads. This property was used by both AC and S caregiver dyads experiencing all three stages of dementia with the exception of dyad 1. In the early stages, simplifying was related to planning ahead in order to ease the process of preparing and cooking the meal. In dyad 5, PWD5 would prepare a large quantity of food with her personal care worker (PCW) and then freeze the remaining portions so that she was able heat it up unassisted in the microwave at a later time. She described this strategy by stating that "some weeks I can prepare extra and freeze it so that on the nights when he (primary caregiver) isn't available I can have something that I can um, prepare." Another strategy for simplifying meal preparation was from CG6 who prepared a sandwich or another kind of light snack for her husband if she was going be away from the home during a mealtime. Meal preparation could also be simplified by having the caregiver take over

the food preparation which was more time efficient and ultimately convenient for the AC dyad in this stage. PWD5 explains that, "Because I take three or four times longer to make something than it would be if he (primary caregiver) just did it, so I realized that it's, it's much easier."

Another simplifying strategy was also used by CG5 who brought take out food into the home, to avoid meal preparation because he was preparing dinner six nights of the week.

As the disease progressed, the dyads in middle stage dementia expanded the strategies that they used to simplify the mealtime experience. Instead of preparing large quantities of food, both the AC and S caregivers explained that they were buying prepared food or complete dinners to ease food preparation. CG4 explained, "Well we've made things so much easier. You can buy the carrots in a bag all peeled and even the small ones. Like he likes to cut them smaller which I couldn't care less but that's okay." CG23 also described that her mom was becoming more reliant on frozen dinners for convenience in her absence, "And then I think you (PWD23) were getting a few more TV dinners just from the grocery store, but you do get tired of those meals prepared the same way, the same flavours." In addition to buying prepared foods, PWD4 simplified meal preparation by making foods that were basic to assemble. For example, the large salad that this S dyad prepared every night for dinner and was described by, "Now, that's our meal, that salad. But if you eat one of those salads that I made, you'll not need to eat anything else." In addition to the strategies already discussed, dyad 19 simplified by limiting the number of people that PWD19 prepared meals for. Traditionally, PWD19 prepared large family meals.

As the disease progressed to the late stage, in all of the four analyzed dyads, the PWDs were completely dependent on the primary caregiver or PCW providing a meal for them. In the AC dyads in this stage, simplifying was related to making food preparation more convenient by purchasing frozen foods from "M&Ms Meats Shops" or preparing large amounts of food and

eating the leftovers for other meals during the week which was not unlike the previous stages. Much like dyad 5 in the early stage, CG22 described how he planned ahead to simplify making meals when he stated, "It's ... so basically when I cook now I try and plan like about three meals at once. So if I'm barbequing I'll do a bunch of burgers, and then you can just microwave them to get them ready." In addition to these specific strategies, like in the early stage dyads, dyad 13 and dyad 17 brought take out food into the home for their convenience, but on a limited basis.

Adapting the setting. This property was identified in eight dyads, with the exception of the AC caregivers in the late stage of dementia. In the early stage, all of the dyads focused on both the physical setting which included the comfort of eating in the home as opposed to a "noisy and distracting" restaurant or being able to "watch the birds" from one's own kitchen table. PWD 5 described the strategy of being more comfortable in her own home as:

Restaurants now for me actually sometimes can be distracting. There's too much noise and stuff and then you can't really carry on a conversation or the waitress is always interrupting and asking how your food is, so I'm actually more comfortable at home for mealtimes.

Creating an inviting "atmosphere" was another important part of this strategy for dyads in the early stage, which included being "relaxed" at mealtimes and having a comfortable temperature in the environment in order to enjoy the meal. PWD 6 explained that "It's the atmosphere that makes the difference to me. I don't like the cold ..." Additionally, all of the dyads spoke to the importance of having the opportunity for socialization and just "being together" during the mealtimes. A social environment that suited the needs of the PWD was an important factor in creating a pleasant dining experience.

Adapting the setting was a strategy that did not evolve to a great extent as dementia progressed to the middle stage. Like in the early stages, all of the dyads focused on the strategy of creating an inviting atmosphere. For these dyads it included reducing distractions by turning off the television or alternatively listening to a radio program, and socializing with friends, family and each other. Dyad 23 explained that having guests created an appealing atmosphere for the meal: "It's funny situations that he sometimes finds himself in. He *lifts* our spirits when he comes."

While this property was discussed by dyads in the early and middle stages, it was not as evident in the late stage interviews. However, CG 1 described that her husband had a better appetite when he was surrounded by friends and family during the mealtime, and stated, "When there are more people he has a better appetite."

Preparing an appetizing meal. Preparing an appetizing meal was a property that was prevalent in eight dyads across all stages of dementia. In most dyads the caregivers were responsible for preparing the meal. Therefore, this property was focused on the caregiver strategizing ways to make meals that they knew would either be appealing or tasty to the PWD.

This strategy was used by dyad 5 where the caregiver made a meal that pleased him but with the condition that PWD5 would enjoy the meal too. For example, PWD5 described "[CG5] knows a little better specifically which of those items I like better. Because he's here and preparing the food." Therefore, while the caregiver was not compromising on what was palatable to him, he also did not have to prepare a separate meal for his mother by using this strategy.

Preparing an appetizing meal was a strategy that evolved in the middle stages of dementia. In this stage the dyads were more mutually involved in preparing an appetizing meal because both the PWD and the caregiver were involved in the meal preparation in all three of the

sampled dyads. For this stage of dementia, preparing an appetizing meal meant that it should be tasty and in some cases, visually appealing. Similar to the early stage strategy, these dyads also prepared foods that both members of the dyad enjoyed. PWD19 explained that “We like preparing things that we both like and are tasty, you know, and attractive looking.”

Transitioning from the middle to late stages of dementia, strategies proved to be especially important for dyad 1 where PWD1 had a poor appetite. Like in the previous stages, it was important for the caregiver to know the PWD’s taste so they only had to prepare one meal; however in dyad 1, meals had to be more specifically tailored to him. An example of this was when CG1 told that “Lots of times now if he tastes something he doesn’t like, he picks it apart. He take[s] it out with his fingers. We find we have to put less in the food.”

Another facet to this strategy in the later stages of dementia was controlling the portion size to create an appetizing meal for the PWD. In all of the late stage dyads, the caregivers limited the portion size; however they were motivated by different factors. In dyad 1 where the PWD had a poor appetite, the CG1 either limited the portion sizes herself, or instructed the PCW to do so. She felt that by taking this step it would entice her husband to eat at least some of his meal. If this strategy was not employed she described that “He wouldn’t even touch [the meal]. He would say, “That is too much, too much, I don’t even want to see it.” A similar strategy was used by CG17 as she wished to give her husband the satisfaction of finishing his meal. She explained that:

Because sometimes he, he sort of dawdles, but he usually eats all his dinner. But I never give him too much, never overload his plate, so that he has the satisfaction of saying, ‘well that was a good dinner, I really enjoyed.’ And I can say, ‘yeah, you ate the whole thing.’

Eating out. This property was identified by 80% of the dyads, with the exception of adult children in the later stages, who ate outside the home setting very rarely in the company of the PWD. I note however, that in the late stage dyads, only dyad 17 still ate outside of the home in a restaurant setting for pleasure. In all stages of dementia, eating out provided an opportunity to try new foods and atmospheres for dining for most of the dyads. An example of this strategy from dyad 12 was:

That’s why we like to go to different restaurants that we’ve never been 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 like to experiment.

This strategy was even employed into the later stages of dementia, where CG17’s love of fine dining had the dyad eating out and enjoying food that she would not prepare in the home setting. An example from CG17 was, “The name of the restaurant ... is Zest. It is *scrumptious* food. You could take anybody there, and it would be just gorgeous.”

Another way in which this strategy was used for dyads in the early and middle stage was to provide an escape from the mundane task of preparing meals. This motivation for eating out was exemplified by CG6 when she stated that, “I like the change. I don’t have to think about what to fix, or prepare it.” This sentiment was echoed by PWD19 who explained that “I would say basically it’s-- and no preparation and no clean up, you know. It’s very pleasant.”

Eating out for a chance for socialization was another strategy that was used across all stages of dementia and by both types of caregiver dyads, with the exception of the AC dyads in the late stages of dementia. The participants in the sub-sample used this strategy to enhance their dining experience when eating outside of the home by enjoying the companionship of friends and family. This strategy was best exemplified by CG4 when she explained:

Well we enjoy the people that we are with very much. Most of ... the ones of course that come out, we all enjoy each other. And we fool around a lot. We can be quite off colour at times. That could upset the odd person but we don't care. Um. It's just very friendly. We all obviously like eating. We all like to try different restaurants. And uh, so it's social, and it's eating. It's fun.

In addition to the strategies above, PWD5 identified that she had created strategies in order to deal with the challenges of eating outside the home. This participant had discovered that she needed to choose places when eating out that she was familiar with and it was important to her that she knew the menu. For her, this helped her to select menu items with more ease as she confessed that ordering off the menu could be challenging if there were too many options. Another complimentary strategy that PWD5 used was bringing along a friend to "be that buffer" when enjoying a meal out of the home.

Adapting to and accommodating the needs of the PWD. This property was identified by 60% dyads and was described in a variety of ways by the caregiver dyads. The most common adaptation that the dyads experienced in all stages of dementia was the shift of mealtime responsibilities to the caregiver. This strategy was especially evident in all four of the AC dyads, where these adult children were involved in preparing a meal for or with their parent since their diagnosis. The shift in mealtime responsibility was not limited to the AC dyads. For example, PWD19 was primarily in charge of meal preparation before her diagnosis and since, CG19 has had to take on more responsibility in the kitchen. In the first year interview CG19 described, that in terms of meal preparation, "I do more work on them now than I used to. I didn't use to do anything." By the second year interviews this caregiver had accommodated his wife's changing needs even more when he explained that,

I'm doing quite a lot of it, yes. Like I do the breakfast, clean up, and then the lunch, and clean up. And I set the table and I do quite a lot of the dinner, sometimes. The odd time I do the whole thing.

Aside from this common strategy used across all stages of dementia, the following examples of adapting to and accommodating the changing needs of the PWD were as diverse as the dyads themselves.

In the early stages, two unique strategies were identified by both types of caregiver dyads. PWD5 described that CG5 had to adapt his social and work schedule to accommodate her need to have her dinner meals prepared. PWD5 explained that, "On occasion [CG5] come[s] from someplace, where like he was going out at night and between work and going out he's come home and made sure that I've got supper and then had to leave again." Another example of a strategy that dyad 6 used to accommodate the changing social needs of the PWD was selecting company to dine with that were very "understanding" of his diagnosis and his loss for words during mealtime conversation.

Much like the early stages of dementia, the strategies used by the AC and S dyads in the late stages were diverse in nature, with the exception of having snacks available to the PWD for frequent and or small meals. In dyad 1, the CG1 accommodated the changing needs of PWD1 by allowing her husband to "enjoy" his meal, even if it meant that he engaged in behaviours that would not be considered traditionally or socially acceptable. For example CG1 explained, "... he eats it how he wants. I let him enjoy it. If he wants to eat it with his fingers, then, let him enjoy it." CG1 also changed up the menu to accommodate PWD1's changing tastes in a process of trial and error and stated that, "If he doesn't eat, what can I do the next? Maybe, I will find something for him. And then he can try it." A complimentary strategy used by the CG22 was

being flexible in terms of preparing and serving a meal to the PWD when she was hungry, rather than offering meals on a schedule.

Encouraging gently. This property was identified by 40% of the dyads, and was notably absent in all of the early stage dyads as shown in table 8. While only 40% of dyads used strategies that involved gently encouraging the PWD, it is important to reveal these strategies were predominantly used by dyads that were experiencing more late staged dementia. It was apparent from the sub-sample, that the PWDs exhibited behaviours such as becoming distracted or forgetting about the meal, and therefore a lower percentage of the total dyads identifying this property was acceptable. In the first year interview, CG4 noted that she 'bug[ged]' her husband to eat more for the lunchtime meal because she felt that he was not consuming enough food on his own. She told PWD4, "but you're not eating enough," in an attempt to get him to eat more. At this point, the dyad was eating separately for both the breakfast and lunch meals. By the second year interviews, this caregiver found that the "encouraging gently" strategy was ineffective and that she actually had to get involved in the lunchtime meal preparation in order for PWD4 to eat more.

In the later stages of dementia this strategy was in a different context because the PWDs were generally not involved in the meal preparation. For example, CG1 used this strategy in order to get her husband to eat his meal or at least a portion of it. One of the ways that this strategy was used by dyad 1 was by 'reminding' her husband to finish his meal, which was exemplified by the following examples, "When something taste[s] (good) that he likes, then he doesn't have to be reminded, but if it is something he doesn't like, I have to be 'please eat. You have to finish your dinner,' as well as "And I keep on, until he says, 'I'm sorry, no more, I'm full up to here (*gestures to forehead*).' And then I stop." To CG1 it was important to avoid

aggravating her husband because he lost his appetite and that was why she was very "gentle" and nurturing when she encouraged him. However, she stated that if her husband was not eating at all, then she has to be more "firm" with him, which was exemplified in the following approach:

Interviewer: So, do you ever have to be firm with [PWD] to get him to eat. Use a technique like that, say, [PWD1], you have to eat?"

Caregiver: No, I tell him, because he has to eat or he will get very weak. And that he needs his strength, and that he could DIE if he didn't eat. Well, that works, he will take another three, four spoonfuls.

Strategies to Promote a Sense of Self

This category was present across all stages of dementia and common to both types of caregiver dyads. The strategies that promoted and maintained the PWD's dignity and sense of self during mealtime were mutually used by both members of the dyad during the early and middle stages of dementia. However, by the late stages, it was apparent that the caregiver was solely responsible for determining and using strategies that promoted a sense of self in the PWD. The most common strategies that were used across the span of the disease focused on both members of the dyad maintaining their pre-morbid mealtime roles.

The following describes the six properties that participants identified in the interview transcripts. The properties related to promoting a sense of self were: 1) working together; 2) taking a sensitive approach to suggestions for PWD; 3) teaching; 4) adapting to and accommodating the changing needs of the PWD; 5) praising; and 6) maintaining the PWD's sense of control. It is important to note that not all properties had a high percentage mention in the data set. I feel that it is essential to describe these properties and the strategies used by the dyads, as the dyads only represent a portion of the total sampled in the primary study. In

addition, all of the dyads were unique and experienced varying degrees of dementia symptoms. Therefore, it is important to describe the emerging properties here, regardless of frequency. See Table 9 below for a summary of the properties' inclusion according to dementia stage and caregiver type.

Working together. In the early and middle stages of dementia, both the AC and S caregiver dyads engaged in strategies that focused on the PWD maintaining their independent or interdependent role related to mealtime preparation and cleanup. By employing this strategy, the PWDs were able to remain useful and have a sense of purpose in the mealtime experience. In the early stages, not one of the sampled PWDs independently participated in the mealtime preparation, however, they did contribute by helping with the cleanup process. This strategy was exemplified by CG12 when she explained that, “He [PWD12] might go out and make soup, but no, as a general rule, he does not go out in the kitchen. But he cleans up every night. He decided that that was fair.”

Table 9
Coding Framework: Strategies Used to Promote a Sense of Self

Category	Properties (Percentage of Total Dyads)	Early (Included YES/NO)	Middle (Included YES/NO)	Late (Included YES/NO)
<i>Strategies Used to Promote a Sense of Self</i>	Working Together 8/10= 80%	YES S 2/2 AC 1/1	YES S 2/2 AC 1/1	YES S 0/2 AC 2/2
	Taking a Sensitive Approach to Suggestions for PWD 7/10= 70%	YES S 0/2 AC 1/1	YES S 0/2 AC 1/1	YES S 2/2 AC 2/2
	Teaching 2/10=20%	NO	YES S 1/2 AC 1/1	NO

Category	Properties (Percentage of Total Dyads)	Early (Included YES/NO)	Middle (Included YES/NO)	Late (Included YES/NO)
	Adapting to and Accommodating the Changing Needs of the PWD 1/10=10%	YES S 1/2 AC 0/1	NO	NO
	Praising 1/10=10%	NO	NO	YES S 1/2 AC 0/2
	Maintaining the PWD's Sense of Control 1/10= 10%	YES S 0/2 AC 0/1	NO	NO

Note. S indicates a spousal relationship; AC indicates an adult child relationship; X/X indicates the number of dyads which included the property

Another strategy that dyad 5 used was getting the services of a PCW who could supervise her once a week in the kitchen so that she could maintain some independence and make a meal

for her caregiver. She explained the importance of using this strategy by stating, "And if I had not had that (the assistance of a PCW to prepare meals), you feel less as a person," and:

Well, I guess it's just being able to cook because, I um, its one of the things I can't do on my own, so, it allows me to...ah, continue to be able to do that. So its still giving me a certain amount of independence, although I even have to be supervised I can still at least physically do it.

As the disease progressed to the middle stages, the AC and S caregiver dyads were working together during mealtime preparation, so that the PWD remained involved. Maintaining independence at this stage meant engaging in strategies where each member of the dyad had their own task but they worked as a team to prepare the meal. This strategy was exemplified by dyad 23 as the caregiver asked her mom to "just put on a pot of rice" and then explained that she would bring the "meat and vegetable" to her mom's house and when she arrived then "the rice would be cooked." This type of strategy was also used by CG19 who explained that "Well I take it over and maybe scrape the plates and clean them off and then put them in the dishwasher. And [PWD] does the big pots and pans. And I'll dry them. So it's a combination effort idea." Another strategy that dyad 19 used to help maintain the sense of self for PWD19 was having CG19 assist and monitor her when she made a complex meal. Rather than CG19 just taking over, he would just "check what she (PWD19) is putting in because she can't remember."

As dementia progressed in the late stages of dementia it was clear that there was a regression from the previous stages, so that the independence and decision making capacity for the PWD was negatively impacted. As a result, the PWDs were limited to making small contributions to mealtimes. The specific strategies that the AC caregivers used were encouraging the PWD to independently make a light lunch or snack, or to help to set or clear the table. CG22

used the strategy of “training” his mother to chop a single vegetable at a time to help him in mealtime preparation. In this dyad, using this strategy served not only to promote the sense of self of PWD22 but also helped CG22 to feel like less of a “galley slave” as the meal preparation was no longer a reciprocal process.

Taking a sensitive approach to suggestions. This strategy was used by caregiver dyads experiencing all stages of dementia (70%). PWD5 described the strategy that her son used as giving her subtle physical cues if she made a mistake. She used the example of when she sat down at the wrong place at the kitchen table; her son would simply “place his water glass in front of her” to signal that she has made a mistake. As the dementia progressed to the middle stages, CG 23 used subtle verbal cues when making mealtime suggestions to her mother. This caregiver used the verbal example of “You know I think it will be much easier for you to.” This caregiver also explained her reasoning for using this approach to this strategy as, “you know, always [phrasing] in terms of the benefits to her, rather than any kind of judgment about whether it’s a mess, or what other people might think or anything like that.” This caregiver was very sensitive to her mother’s feelings and sense of person and therefore was very careful to phrase suggestions so that they do not seem like orders.

As the disease progressed into the later stages, all of the dyads made the conscious effort to “save face” for the PWD by forgiving mistakes or unusual behaviour during the mealtime experience. CG22 explained that his mom rarely had the inclination to prepare a meal; however when she did, it was generally not appetizing to him. For example:

CG22: There was one day about six months ago she decided she was going to make something. It was something quite bizarre. It was like salad with yogurt and raisins or something. [laughs]

Interviewer: So what did you do about that?

CG22r: “Hey thanks Mom” and then she forgot about it. She cleaned it up. [laughing]

But I don’t know, it’s just like every once in a while she’ll do something.

Another example of this property was when CGI took a sensitive approach when her husband engaged in behaviour that would be considered unusual compared to his pre-morbid state and explained that “He doesn’t put [it] on the table (piece of food), he puts it into a piece of Kleenex. And then he puts it into a ball, and he might spit into it.” She feels that she must “forgive” her husbands behaviours in order to promote his sense of self and explained that:

If you are angry, then, you make him ashamed of himself, and people understand. He doesn’t speak much, but he understand[s], and something like that would hurt him. I can feel that. So, I try to be patient. Because many times when he, no matter how much you try not to get upset, sometime, it happens, and I get upset. But, he always tell me. ‘Don’t be mad at me, please don’t be mad.’ How I can be mad then?

For this dyad it was important that the caregiver not constantly “correct” her husband to save his feelings and explains that “I say, I don’t correct you (PWD1) constantly, because he doesn’t like the correction[s] constantly.”

A last example of a strategy that CG17 used to save face for her husband was redirecting after he asks about the timing of the meal. She uses this example:

And I said, ‘ok, we’ll wait for awhile, and we’ll have supper later.’ Well, I could make it twenty minutes later, and that’s still later, and I notice that, that more and more he’s, time doesn’t really mean anything, you know. Like as long as it’s a few minutes later, he thinks it’s late enough.

Teaching. This strategy was used by only 2/10 dyads, experiencing the middle stages of dementia. Dyad 19 mutually recognized that PWD19 was primarily responsible for preparing the meals, and that likely this responsibility would eventually fall on the shoulders of the caregiver as her dementia advanced. In the first year interview, PWD19 explained that she started to teach her husband how to cook and said:

Cause I said to him, 'well I know I have Alzheimer's. At the moment it's not a problem.' But I said, 'I think it would be a good idea if you to learn to cook.' So he thought it was a good idea too. So he can whip up a pretty good dinner.

Not only did this strategy serve an obvious practical purpose, it also promoted the self worth of the PWD by allowing her to use her faculties and pass along her knowledge of cooking to her husband. A similar strategy was used by dyad 23 where the PWD23 enjoyed passing along her recipes and methods of cooking to her daughter.

Accommodating the changing needs of the PWD. Much like the previously described property, Accommodating the Changing Needs of the PWD was only acknowledged and described by dyad 6. This property was exemplified by the couple when they insisted that the pace of conversation during social outings or family get-togethers be slowed so that PWD could follow along and equally participate in the mealtime conversation.

Praising. Praising was used by CG17 who took the opportunity to praise her husband's accomplishments at mealtime. In this case, she served her husband smaller portions of food so that he felt a sense of accomplishment when he finished the whole meal. She explained that by praising she could, "put some good about his day in to him, while he can accept it. And you know there's going to come a time that he's not going to understand even what I'm saying, at all. So if I can make him feel good at all, I do. In any little way."

Maintaining the PWD's sense of control. In the early stages of dementia, there was only one dyad that identified this property. PWD5 described the strategy of maintaining her sense of control (and thus sense of self). She explained that she used this strategy by deciding when, if and what meals, she and the caregiver would eat together. Since they lived in the same house but had different apartments, this strategy was easily facilitated.

Strategies Used to Minimize Safety Risks

This category like the others was used universally across the different types of caregiver dyads and stages of dementia. In general, the data suggested that the caregivers were cognizant of the safety risks that PWDs posed to not only to themselves but to others in the household during meal and snack preparation. I noted that in the early and middle stages, both the caregiver and PWD mutually agreed to strategies that minimized safety risk in the kitchen. However, as the dementia progressed into the later stages, it was the caregiver who was responsible for strategizing and assisting the PWD to minimize risk. The most significant finding from this category was that in all stages, the dyads recognized that because of the diagnosis, the PWD's participation in mealtime preparation needed to be altered to limit the risk that they posed to themselves and the household.

The following will describe the four specific properties used by participants in each stage of dementia as it progressed from early to late. The strategies related to minimizing safety risks that the participants described were: 1) accepting the limitations of the PWD; 2) modifying; 3) teaching and reinforcing; and 4) removing danger. Again, like the previously described categories, not all properties are identified by a high percentage of dyads. However, it was important not to exclude the properties, because only a portion of the dyads were sampled, and

therefore may prove useful to the coding framework for the entire data set. See table 10 below for a summary of the properties' inclusion according to dementia stage and caregiver type.

Accepting the limitations of the PWD. This property was the most widely acknowledged property across both caregiver dyad types and stages of dementia (50%). In the early stages, PWD5 accepted that because of her forgetfulness, she should not use the stove or attempt to make a dish that required a complex recipe. In fact, PWD5 related a story where she used dish soap instead of oil to brown the meat required for the meal. In this case, she accepted this limitation and agreed that she needed to be supervised by either her caregiver or PCW in the kitchen and explained that "we always maintain the safety factors, but there are things that I can still do if I'm supervised."

This type of strategy continued into the middle stages where PWD23 and PWD19 were still able to participate in meal preparation. However, these PWDs were cognizant that they were limited by their forgetfulness and could either rely on the assistance of their caregiver or simplify their cooking tasks. For example, CG19 assisted his wife when she added food ingredients in a dish so that she did not "miss anything", or alternatively, "double up" on something else. Another example was CG23 encouraging her mother to simplify meal preparation and explained that "I don't have any particular concerns and as long as you're [PWD23] not trying to do too many things at once." In this dyad, when PWD23 prepared food alone, she knew that her memory was limited, and her resulting strategy was to be conscious of all the steps that she needed to take when preparing meals and trying not to make a mistake.

Table 10

Coding Framework: Strategies Used to Minimize Safety Risks

Category	Properties (Percentage of Total Dyads)	Early (Included YES/NO)	Middle (Included YES/NO)	Late (Included YES/NO)
<i>Strategies Used to Minimize Safety Risks</i>	Accepting the Limitations of the PWD 5/10=50%	YES S 0/2 AC 1/1	YES S 1/2 AC1/1	YES S 0/2 AC 2/2
	Modifying 4/10= 40%	NO	YES S 1/2 AC 1/1	YES S 0/2 AC 2/2
	Teaching and Reinforcing 2/10=20%	NO	NO	YES S 1/2 AC 1/2
	Removing Danger 2/10=20%	NO	NO	YES S 0/2 AC 2/2

Note. S indicates a spousal relationship; AC indicates an adult child relationship; X/X indicates the number of dyads which included the property

By contrast, in the later stages, the PWDs' involvement in mealtime preparation was virtually non-existent; either due to their limited abilities (all caregiver dyads) or the tradition of having the wife or PCW prepare the meals (both spousal dyads). In the case of the AC dyads, the caregivers and PWDs accepted that it was no longer safe for the PWD to use the stove or oven and therefore used the strategy that they would not use these appliances.

Modifying. Another property was modifying appliances' appearance and structure, which was identified in 40% of the dyads. CG23 described that PWD23 once had an incident that involved the stove tipping forward while she was using it alone. To help minimize risk to PWD23, the oven was tethered to the wall to prevent another accident. Another practical strategy identified in this stage by dyad 19 was placing a piece of red tape on the oven's on/off switch to draw attention to it when the PWD was in the kitchen working. It served as a reminder to her, to switch it off when she was done preparing dinner. Modifying was also used into the late stages, where CG22 encouraged his mother to make and obtain snacks during the day time. In this dyad, CG 22 took the suggestion of a friend and decided to place an "orange sticker on the 30 second button on the microwave." He explained that making this modification minimized the risk of his mother overheating anything that she might put in the microwave, preventing both burns and fire.

Teaching and reinforcing. By the late stages of dementia, 2/4 dyads used teaching and reinforcing strategies to help minimize risk to the PWD. CG17 taught and subsequently reminded her husband with later stage dementia that he could not go near the stove. She admitted that this was more of a proactive strategy, as her husband had never been involved in meal preparation; however she wanted to minimize risk for him. Another teaching strategy that was

used by CG22 was teaching his mom how to use the modified microwave as explained in the previous property.

Removing danger. The final property that was identified by the AC caregivers in the late stage was the proactive strategy of removing danger (2/4 dyads). CG22 explained that when he lived apart from his mom he became increasingly concerned about his parent's safety. His resulting strategy of removing the danger was explained in the following:

Well it got progressively worse. And then, you know, she'd still try and reheat stuff on the stove down there. And finally I just threw all the pots and pans away. Just because I was afraid she'd burn the house down.

A similar strategy was used by CG23 and she explained that she "remove[d] the automatic kettle" from the kitchen if she was going to leave her mom at home unattended to prevent any accident.

Strategies to Promote the Caregiver's Sense of Self

Both the AC and S caregivers of PWDs across all stages of the disease had strategic ways to cope with the changing needs of the PWD at mealtime. The participant caregivers in the sub-sample developed strategies that they followed in order to relieve or reduce the caregiver stress that they experienced during mealtimes. I found that there was not a lot of overlap in the use of the strategies. Again, I included all of the identified properties, as they will serve to inform the coding framework which may be used to analyze the entire primary data set. Overall, there were nine properties including: 1) eating apart; 2) getting outside help; 3) accepting changes in mealtime behaviour; 4) accepting new roles; 5) channeling stress; 6) recognizing boundaries; 7) being patient; 8) praying; and 9) keeping up a 'normal routine'. See Table 11 below for a summary of the properties' inclusion according to dementia stage and caregiver type.

Table 11

Coding Framework: Strategies to Promote the Caregiver's Sense of Self

Category	Properties (Percentage of Total Dyads)	Early (Included YES/NO)	Middle (Included YES/NO)	Late (Included YES?NO)
<i>Strategies to Promote the Caregiver's Sense of Self</i>	Eating Apart	YES	YES	YES
	5/10= 50%	S 0/2	S 1/2	S 0/2
		AC 1/1	AC 1/1	AC 2/2
	Getting Outside Help	YES	NO	YES
	3/10= 30%	S 0/2		S 1/2
		AC 1/1		AC 1/1
	Accepting Changes	YES	NO	YES
	Mealtimes Behaviours	S 1/2		S 2/2
	3/10= 30%	AC 0/1		AC 0/1
	Accepting New Roles	YES	YES	NO
	3/10= 30%	S 0/2	S 2/2	
		AC 1/1	AC 0/2	

	Channeling Stress	YES	NO	NO
	2/10= 20%	S 1/2		
		AC 1/1		
	Having Patience	NO	NO	YES
	2/10= 20%			S 2/2
				AC 0/2
	Recognizing Boundaries	YES	NO	NO
	2/10= 20%	S 1/2		
		AC 1/1		
	Praying	NO	NO	YES
	1/10= 10%			S 1/2
				AC 0/2
	Keeping up a "normal routine"	YES	NO	NO
	1/10= 10%	S 0/2		
		AC 1/1		

Note. S indicates a spousal relationship; AC indicates an adult child relationship; X/X indicates the number of dyads which included the property

Eating apart. Eating apart was identified by 50% of the dyads. Interestingly, all of the AC dyads ate apart at least one meal of the day. In both the early and middle stages the adult children lived separately from their PWD and therefore, eating apart was easily facilitated. An example of a strategy used was from CG22 who explained that "The [PCW] will make whatever meal, you know, breakfast or lunch, depending on what time they come in. ... And then I do supper." Eating apart could also be facilitated when the PWD went out to a senior's day outing and a meal was provided in both the middle and late stages of dementia.

Getting outside help. This property was identified by 30% of the dyads. Getting assistance from people outside of the home was notably absent with caregivers of PWD in the middle stages. This strategy predominantly involved having PCWs, arranged through the local community healthcare centre or Alzheimer's group, to come into the home and either provide a meal for the PWD or assist them to make it. In the case of CG1, she explained that:

You get used to it (accepting outside help). You have to accept. I didn't like it when I was stronger. I preferred to do it all myself. But now, I can't do it. I have to accept it. I don't like, but I have to.

This strategy also meant relying on family members to make food for holiday get-togethers. For example, CG1 stated that "The whole family is coming here, but they are making and bringing the turkey, and food." In addition, this strategy also meant getting mealtime suggestions and ideas from people associated with supports groups.

Accepting changes in mealtime behaviour. This property was used by 30% of the dyads. For example, PWD6 could get distracted during the mealtime by his difficulty with word finding. At mealtimes he would either get up from the table to "look for a dictionary" to help him find a specific word or alternatively sat at the table and engaged in the same activity. In this dyad, CG6

got upset by this behaviour but had since learned to accept it and finish her meal without him. She explained that "I'm going to eat mine [her meal] when it's hot." While there were no such disruptive behaviours described by the caregivers of middle staged PWDs, caregivers of PWDs in the later stage explained that they had also come to accept these behavioural changes at mealtime. CG1 exemplified a strategy by:

Interviewer: So, you haven't noticed any changes that way, where you might have to ask him to take a Kleenex and wipe his mouth.

Caregiver: Oh, many times I wipe him. Or ask her (friend of the dyad) for a towel or something. But everybody understands. And I am not ashamed of it."

Accepting new roles. This property was used by caregivers of PWDs in both the early and middle stages (30%). For example, CG5 willingly took on meal preparation for the dyad and explained that "Oh it doesn't bother me any, I like to cook." By contrast, CG4 did not especially enjoy cooking, however accepted her husband's limited abilities related to meal preparation and provided meals for her spouse.

Channeling stress. This property was acknowledged by only 20% of the dyads. An example of a strategy used in this property was by CG5 when he explained that any pent up stress that resulted from not only mealtimes, but care-giving in general he could "usually get out at work." In fact, this caregiver avoided caregiver stress by taking a relaxed approach and remaining calm during mealtimes. In addition, CG6 used activities such as going to "Curves" to take care of herself and rid herself of frustration.

Recognizing boundaries. This property was also used by two dyads experiencing early stage dementia. For example, CG5 recognized that "we don't work well together," and preferred

to prepare their meals alone. He coped with his mother's mealtime behaviours by removing her from the preparation process so that he did not become "stressed out".

Having patience. This property was identified by dyad 1 and dyad 17. CG1 acknowledged that she had to be patient with PWD1 and by doing this she felt that all of his behaviour changes and challenges during mealtime would be "all right." She further explained that "I try to begin everyday with this, because you need lots of patience, that's the most important thing."

Praying. This property was also only used by dyad 1. This caregiver used prayer to help give her strength to care for her husband during mealtimes.

Keeping up a 'normal routine'. This property was identified in dyad 5. During mealtime, CG5 tried to keep a normal routine by cooking things that he liked and would enjoy cooking, without first consulting the PWD. He kept up his normal routine just like before his mom's diagnosis and his involvement with preparing her meals. This strategy was exemplified by the caregiver when he said "I just grab whatever I feel like eating and then she gets it. You know it could be anywhere from Kraft dinner to ribs, it just depends on what I feel like eating."

To summarize, this chapter presented a detailed but succinct description of the data after engaging in the secondary analysis. In total, I identified 4 categories which included 1) strategies to facilitate eating; 2) strategies to promote a sense of self; 3) strategies to minimize safety risks; and 4) strategies to promote the caregiver's sense of self. These categories were described and synthesized according to their properties derived from the strategies that were identified in the data set. In the following chapter I will provide a deeper level of analysis of the findings as well as relate them to the literature. I will also answer my research question and sub-questions which

focused on discovering what mealtime strategies are used by caregivers in the community to cope with behavioural changes during mealtimes.

Chapter Five: Analysis

Chapter five expands upon the description of the data in the previous chapter by providing a more in-depth analysis of the findings. It will also present my interpretation of the answers to my research question and sub-questions stated in the third chapter. My interpretations are related to relevant literature in order to give them context and relevance.

Research Question

What mealtime strategies have dyads consisting of a person with advancing dementia and their spousal or adult child caregiver living in the community developed to cope with dementia behaviours as the disease progresses?

A variety of strategies were used by the dyads in order to cope with the changes in behaviour that were caused by the progressive dementia at mealtime. These strategies were classified according to the four categories that were identified in the previous chapter. Please see table 12 below for a summary of the strategies that were identified by the sub-sample of dyads.

Overall, I felt that the interview transcripts from the primary study provided sufficient data from which I could discover the strategies that the dyads used to cope with dementia related behaviours at mealtime. While the primary study's research questions centered on generally exploring the mealtime experience, I was able to identify 88 strategies that were used by the sub-sample of ten dyads. Although, I felt that it was important to not disregard any of the identified strategies in order to more fully inform the primary research team, I also considered their use for the dyads in the community. Despite the small sample size, I believe that the strategies identified by the dyads in the sub-sample may be useful to others living in the community, even if a strategy was only highlighted by one family. For example strategies related to praying was only highlighted by dyad 1, however, I believe that other dyads living in the community should be

able to have the opportunity to consider the strategies related to this property. Therefore, inclusion of all of the 88 strategies will not only help to inform the primary research but dyads living in the community as well.

On the whole, the strategies that were identified in the data could reasonably be used by dyads in the community setting because they were practical and showed common sense reasoning in their development and use. For example, reducing distractions by turning off the television or placing an orange sticker on the microwave button were easily facilitated by dyads living in the community. However, some of the strategies used by the dyads may not be as easily used in certain circumstances.

Table 12

Strategies Used By Dyads to Cope with Dementia Behaviours in the Community

Category	Strategies
Strategies Used to Facilitate	Adapting the Setting
Eating	<ul style="list-style-type: none">• Invite additional family members to the meal• Reduce distractions e.g. turning off the television• Create a comfortable environment e.g. turning on the radio during the meal, watching the birds• Control the temperature Preparing an Appetizing Meal <ul style="list-style-type: none">• Know specific tastes and preferences of the person with dementia (PWD)• Instruct the personal care workers (PCW) to make an appetizing meal• Create visual appeal• Make a meal that will be mutually enjoyed by the dyad• Control the portion size Gently Encouraging <ul style="list-style-type: none">• Avoid nagging• Use “soft and gentle” reminders• Be firm if “soft” approach does not entice PWD to eat• Become physically involved in assisting the PWD if verbal encouragement does not work

Category	Strategies
Strategies Used to Facilitate	Adapting to and Accommodating Changing Needs
Eating	<ul style="list-style-type: none">• Allow flexibility for mealtimes• Maintain a routine• Facilitate the enjoyment of the meal for the PWD e.g. allowing them to eat with fingers or pull food apart• Mix up the menu• Select people who are understanding of the diagnosis to dine with• Ensure a meal for the PWD during a busy work and social schedule Simplifying to Embrace Convenience <ul style="list-style-type: none">• Prepare large amounts of food and freezing it for later use• Buy convenience foods from M&M Meat Shops• Buy pre-made frozen dinners• Bring take out food into the home• Use Meals-On-Wheels• Simplify complexity of meals• Buy single serving sizes• Limit party size to cook for

Category	Strategies
Strategies Used to Facilitate Eating	<ul style="list-style-type: none"> • Pre-prepare light meals and snacks for the PWD in the caregiver's absence <p>Maintaining a Routine</p> <ul style="list-style-type: none"> • Observe mealtimes • "Honour" a specific seat • Eat in the same environment e.g. at the kitchen table or in front of the television • Plate the food vs. serving family style • Say a prayer before the meal • Prepare an appetizer • Observe holidays traditions • Embrace before the meal <p>Eating Out</p> <ul style="list-style-type: none"> • Eat out to provide a change for the mundane routine • Eat out to provide an escape for preparing and cleaning up • Eat out to be spontaneous • Eat out in familiar places • Eat out with others to provide a "buffer" against the symptoms of the disease

Category	Strategies
Strategies Used to Promote a Sense of Self	<p>Promoting Independence</p> <ul style="list-style-type: none"> • Have interdependent roles during meal preparation • Have independent roles during meal preparation and clean up • Assist PWD with complex recipes • Gain outside help to assist PWD with cooking • Modify appliances • Invite PWD to participate in simple meal preparation tasks • Encourage PWD to independently access snacks and light meals • Encourage PWD to help set and clean up the table <p>Maintaining the PWD's Sense of Control</p> <ul style="list-style-type: none"> • PWD decides on the frequency of meals shared as a dyad • PWD decides on where the meal will be consumed • PWD decides on mealtime preparation <p>Teaching</p> <ul style="list-style-type: none"> • PWD teaches caregiver how to prepare meals <p>Taking a Sensitive Approach to Suggestions for PWD</p> <ul style="list-style-type: none"> • Phrase questions as to not push caregiver's agenda

Category	Strategies
Strategies Used to Promote a Sense of Self	<ul style="list-style-type: none"> • Be cognizant of PWD self esteem and personhood • Acknowledge effort to participate in mealtime preparation but not taking corrective action • Do not correct behaviours that are not considered socially acceptable • Redirect questions relating to food preparation <p>Adapting to and Accommodating the Changing Needs of the PWD</p> <ul style="list-style-type: none"> • Slow down pace of conversation for the PWD to follow <p>Look for opportunities to praise the PWD</p>
Strategies Used to Minimize Safety Risks	<p>Accepting the Limitations of the PWD</p> <ul style="list-style-type: none"> • Eliminate the use stove and over for the PWD • Gain the assistance of the CG • Set boundaries • Use microwave instead of oven • Date meat in the refrigerator • Scan food supply for spoiled items • (Caregiver) Bring fresh food for the PWD to prepare • Be Conscious of Food Preparation

Category	Strategies
Strategies Used to Minimize Safety Risks	<p>Removing Danger</p> <ul style="list-style-type: none"> • Remove cooking items such as pots and pans • Remove appliances such as kettle with caregiver away from home <p>Teaching and Reinforcing</p> <ul style="list-style-type: none"> • Show PWD how to use modified appliance • Remind PWD of safety concerns <p>Modifying</p> <ul style="list-style-type: none"> • Tether stove to the wall • Place an orange sticker on the 30 second button on the microwave • Place a piece of red tape on the on/off switch of the oven
Strategies Used to Promote the Caregiver's Sense of Self	<p>Accepting New Roles</p> <ul style="list-style-type: none"> • Accept non traditional "cooking" role <p>Channeling Stress</p> <ul style="list-style-type: none"> • Relax • Getting frustration out at work • Have hobbies <p>Accepting the Negative Mealtime Behaviours</p> <ul style="list-style-type: none"> • Accept behaviours • Do not feeling ashamed

Category	Strategies
Strategies Used to Promote the Caregiver's Sense of Self	<ul style="list-style-type: none"> • Be conscious of the feelings of the PWD during negative behaviours <p>Eat apart</p> <p>Keep up a "normal routine"</p> <p>Recognize boundaries</p> <p>Get outside help</p> <p>Have Patience</p> <p>Pray</p>

Specific strategies may be harder for dyads to use such as those that involve obtaining outside help for mealtimes, inviting additional family members to dine with the PWD, and accepting new roles. First, it may be not be possible for caregivers to obtain the help of PCWs to assist in mealtimes such as described in dyad 22, where the PCW was responsible for preparing two meals each day. Alzheimer's societies, such as the London and Middlesex chapter, offer a Volunteer Companion Program, in which a volunteer will provide a respite service for the caregiver for up to two hours a week (Alzheimer Society of London and Middlesex, 2007). While such excellent volunteer programs exist, in most cases, services that are funded through the government such as the Canadian Red Cross require the PWD to meet certain eligibility criteria before paid help will be provided (Canadian Red Cross, 2008). Therefore, dyads such as those that represented the middle stages of dementia in the sub-sample may have to rely on services provided by Alzheimer's disease support groups, or pay out of pocket for mealtime

assistance. Therefore, it may be difficult for some dyads living in the community to access affordable and/or available services to gain assistance for mealtimes.

In addition to obtaining the outside community assistance, creating an atmosphere that is conducive to enticing the PWD's appetite may prove to be difficult. For example, CG1 explained that her husband frequently had a poor appetite; however he would eat much better in the company of his family. Although it may be beneficial to promote the appetite of the PWD, it may be unrealistic for some dyads to dine with their extended family on a regular basis. Therefore, dyads that are isolated in the community may have difficulty creating this type of dining experience for the PWD outside of holidays and dinner clubs, if at all.

The final strategy that may prove to be difficult for dyads to implement is having the informal caregiver take on the role of providing the meal for the PWD. As mentioned earlier, DiBartolo and Soeken (2003) explained that at least 50% of the primary caregivers are spouses of the PWD, who may indeed be elderly and may be physically unable to take on the all demands associated with providing care for their spouse, like in dyad 1.

Sub-questions

1) How do the strategies relate to distinct stages of the disease and how do these strategies compare?

Overall, the strategies that were used by the dyads were in some cases as unique as the dyads themselves and in others, showed much overlap. I feel that it is important to list these strategies as they were identified from only a portion of the total sample in the primary study and may serve to inform the larger sample analysis. In the following section I describe the strategies used in the different stages of dementia as they relate to the category that I classified them under. I explain how the strategies may or may not be unique to a specific stage, or how they progress

throughout the dementia illness trajectory and I make reference to the literature to support my analysis.

Strategies used to facilitate eating. The category, strategies used to facilitate eating, had the most identified properties and thus, resulting strategies. As displayed on table 8, it was apparent that the properties in this category were used across the span of the dementia illness trajectory. In fact, the property maintaining a routine was used by all dyads, as they described the different ways that they continued to honour traditions. It may seem that routines, such as 'honouring' specific seats at the table or observing holiday traditions were simply the continuation of rituals established by the dyads. However, Rayner, O'Brien and Schoenbachler (2006) support that a PWD can benefit from the consistency of routines. In fact, Rayner et al. assert that adhering to a meal time can reduce stress for a PWD and therefore, the chance of negative behaviours is decreased. In particular, serving meals at a 'set' mealtime is maintaining routine, which is a strategy used in geriatric rehabilitation (Wilken & Isaccson, 2005). This strategy can help bolster the memory, in addition to being a strategy to combat forgetfulness in dementia (Imhof, Wallhagen, Mahrer-Imhoh & Monsch, 2006). Importantly, the notion that PWDs have a greater reliance on accessing their remote memory (Gibson 1994; Parker 1995), supports the continuation of well established and practiced routines which may be recalled from 'remote' memory.

After maintaining a routine at mealtime, the property of simplifying was identified by 90% of the dyads. Indeed, simplifying strategies mainly centered on food preparation, such as buying frozen dinners in dyad 19 or freezing large quantities of food in dyad 22. When analyzing these strategies, I wondered if dyads with dementia were any different from other families living in the community and their need to simplify. However, it is important to note that mealtimes

represented only one facet of life for the dyads dealing with the changes associated with dementia. For example, CG19 who traditionally was not involved in food preparation during his married life had to take on the role of chef. It is reasonable to assume that CG19, aged 90 years, would not prepare complex recipes but rather rely on prepared meals. Subsequently, simplifying was important in the later stages of dementia, where the caregivers were primarily responsible for all of the mealtime preparation and clean up. In addition to their mealtime responsibilities in the sub-sample, they are involved in helping to "wash," "dress," "redirect" and "encourage" their spouse or parent throughout the day. Therefore, it is practical that caregivers would try to make mealtime preparation as simple as possible throughout the stages of dementia. In fact, it is recommended that caregivers simplify their management regimen to the best of their ability in order to avoid caregiver burnout (Kasuya, Polgar-Bailey & Takeuchi, 2000).

Preparing an appetizing meal was another property that was used across all stages of the disease, with strategies that varied according to the stage of dementia. I noted that in the early to middle stages of dementia, the strategies involved creating a visually appealing meal like in dyad 4 or making meals that were mutually enjoyed like in dyad 6. However, the motivation behind the strategies shifted in the later stages as the focus became solely on PWD, rather than the dyad. For example, in the later stages of dementia, PWD1 became particular about what foods he would eat, and therefore preparing an appetizing meal needed to be to his taste rather than to that of the couple. Similarly, in this dyad, there may have been a few attempts to create an appetizing meal, before PWD1 would consume it. Therefore, strategies that centered on the PWD became more of the focus of the caregiver as the disease progressed. These strategies were congruent to those presented by Hellen (1998) in relation to residents in an institution. In the institutional setting, Hellen suggested that staff need to take the initiative to learn the eating preferences of

residents with dementia because she proposes that food and mealtimes “may provide a link to the present” (p. 194).

Similar to preparing an appetizing meal, 80% of the dyads adapted the environment for the comfort of the PWD, to help them enjoy their meal. As in table 8 above, it was apparent that only 50% of the dyads in the later stage of dementia adapted the setting to the PWDs’ liking. I wondered if this was because they were no longer interested if the PWD would notice the little “extras” such as reducing distractions or setting the temperature of the room. I was reminded of working in the continuing care setting, where health care providers were turning on the television or talking with other staff members, for their own enjoyment. At this point in the progression of dementia, I questioned if mealtime was simply a task, and therefore, strategies to enhance the setting were perhaps extraneous? This thought is supported by the work of Schell and Kayser-Jones (1999) who observed staff members in a long term care home, and found that the dining experience of PWDs as simply being fed with little consideration to their location or environmental stimuli.

The next property was eating out with 80% of the dyads identifying this. Strategies that were related to this category seem to be related to the escape from mundane tasks such as preparing and clearing up of the meal in the early to middle stages of dementia. However, these strategies were notably absent in the later stages, where only dyad 17 ate out for pleasure. By the later stages, CG22 explained the only reason that the dyad ate out in a restaurant was for convenience on the way home from the city, as PWD22 did not hold up conversation and fell asleep in the restaurant setting. Therefore, strategies related to eating out may not be appropriate and do not span to the later stages. In fact, in *More food for thought: A report submitted to the Alzheimer’s Society (UK)* (2002), stated that some caregivers ceased to eat out with the PWD

even in the very early stages, while other caregivers continued to dine out with their relative into the late stages (Watson, Manthorpe & Stimpson, 2002). These authors suggest that the reason that family members may not take the PWD out to eat is because their feelings can be negatively affected by dementia behaviours such as making a mess, insisting to take food home, and causing embarrassment or the caregiver’s own inability to relax and enjoy the meal (Watson et al.). Therefore, while eating out can provide a positive social context in which to consume a meal, it may be a greater stress to the caregiver (Watson et al.) and especially the PWD experiencing more advanced dementia and thus is not utilized as the disease progresses (Vogelzang, 2003).

Adapting to the changing needs of the PWD was identified by 60% of the dyads. Based on the sub-sample, all of the caregivers in the later stages explicitly expressed the strategies that they employed to accommodate the changing needs of the PWD. Perhaps, the strategy of being “flexible” best represented this property. Even though Rayner et al. (2006) support that maintaining routines is beneficial to PWDs as outlined in the maintaining routines property, for some of the dyads, having flexibility and being able to adapt their changing needs was beneficial in terms of mealtime efficiency, efficacy and enjoyment. Indeed, Hellen (1998) suggests those caregivers in the institutional setting can help to lessen precursors to negative mealtime behaviour by being flexible and making changes to the time the meal is served, the environment and the food itself to suit the evolving needs of the PWD.

The final set of strategies were related to the encouraging gently property, which not unlike those of the last property, were especially significant in the late stage dementia dyads. With the exception of dyad 13, 75% of the dyads in the late stage used strategies that required the caregivers to encourage the PWD to eat. According to Reisberg and Franssen’s (1999) FAST

staging tool, a PWD can have difficulty with complex activities of daily living during stage 4. Therefore, those experiencing more advanced dementia may have difficulty eating, due to unmet needs in regards to changes to their physical abilities. Thus, strategies to encourage the PWD to eat were significant in this stage as it is well supported in the literature that there is a positive relationship between weight loss and a dementia diagnosis (Griffin, 1995). In addition, it is important to note that this sub-sample did not include dyads that required the caregiver to feed the PWD. At this point, it is important to acknowledge the concept of enabling the PWD during mealtime as described by Wells, Dawson and Kline (1993). In this sub-sample with the exception of dyad 4, coaxing the PWD to eat required strategies based on verbal requests and encouragement. Encouraging gently is a strategy that has great potential to enable the PWD during mealtime. As the disease progresses, it is critical that caregivers evolve their strategies so that they are indeed enabling the PWD to use their existing abilities to eat, rather than taking a "doing for" approach as cautioned against in Hellen (1998).

After reviewing all of the properties and individuals strategies that were present in strategies used to facilitate eating, I was able to further define this category according to stage of dementia. The following provides a definition of the category, strategies used to facilitate eating according to the stage of dementia.

Early stage dementia definition. Pragmatic strategies used by both the caregiver and the PWD to facilitate the taking in of food at mealtime by providing a chance for socialization between the PWD and their caregiver, engaging in practical behaviours, taking chances to eat out or bring food into the home, focusing on an appetizing meal, selecting supportive friends to share mealtimes with, keeping a routine and simplifying mealtime.

Middle stage dementia definition. Pragmatic strategies used by both the PWD and the caregiver that facilitate the taking in of food at a meal by: adapting the setting, simplifying the meal, preparing nutritious and appropriated sized meals and snacks, being together, having the opportunity to socialize, having a routine while remaining flexible, and providing verbal encouragement if needed.

Late stage dementia definition. Pragmatic strategies used primarily by the caregiver that facilitate the taking in of food by the PWD include: enticing an appetite by enhancing the setting, preparing and providing appetizing and appropriate sized meals and snacks, giving verbal encouragement, simplifying mealtime preparation and maintaining routines while remaining flexible.

Strategies used to promote a sense of self. The category, strategies used to promote a sense of self, also had many identified properties. As displayed on table 9, properties could span across the stages of the dementia disease, however some were more specific to certain stages than others. The first example of a strategy that was specifically related to early stage dementia was related to the property of maintaining the PWD's sense of control. Strategies that involved the promotion of the wishes and desires of the PWD recognize that he/she is capable of having a sense of self. Mills and Coleman (1994) state that, "dementia may fragment the personality of the sufferer but the personal awareness of individual uniqueness of being remains until death" (p. 213). Therefore, I suggest that strategies that were used to carry out the expectations of the PWD are important to commence in the early stages of the disease and continue as it progresses.

Another property that had specific strategies related to the early stage was adapting to and accommodating the changing needs of the PWD. Dyad 6 used the specific strategy of asking people that they dined with to slow down the pace of conversation so that the PWD could follow

along. I suspected that this strategy was only identified in one dyad but was a common strategy used in the sub-sample. This is because all of the dyads in the sub-sample tended to dine with the same groups of people on different occasions. Therefore, it is reasonable to believe that the strategy of telling people to slow down their pace of conversation would have only needed to be stated when it became an issue (in the early stage). In fact, Reisberg (1984) suggests that as early as stage 3 or early Alzheimer's disease according to the FAST staging tool, the PWD may have difficulty recalling names or selecting words in social situations. In addition, this strategy may also help to prevent the PWD from socially withdrawing (Pittiglio, 2000) as discussed earlier. If the same groups of people that the dyad dines with are aware of this limitation, they may learn to accommodate it accordingly, and continue to modify how they interact with the PWD as the dementia progresses.

Another strategy that was specific to a single stage of dementia was teaching as identified by dyad 19 and 23. Dyad 19 was experiencing middle stage dementia and they explained that they used the strategy of teaching CG19 how to cook and prepare meals. I infer that while this is a practical strategy, it also served to bolster the self esteem of the PWD who was able to use participate and feel like a contributing member of the relationship. Again, as suggested by Resiberg and Franssen (1999) PWDs may begin to exhibit signs of a decreased ability to perform complex tasks such as preparing and serving a meal as early as stage 4, according to the FAST staging tool. In view of this change, it seems appropriate to take advantage of the remaining strengths of the PWD, and bolster their sense of self by engaging in educational instruction for the caregiver.

Another strategy that was identified in a single stage was praising. CG17 used the mealtime as an opportunity to "put good about his (PWD17) day in to him, while he can accept

it," by praising his ability to finish his entire meal. Using a strategy like praising "while he can accept it," nicely compliments a caregiver's 'best friends' approach to dementia care (Bell & Troxel, 1997). For example, using the 'best friends' approach encourages caregivers to be a friend to the PWD and state that "a good friendship brings out the best in each *person* and builds self-esteem" (Bell & Troxel, p. 54). Bell and Troxel support that frequently giving compliments to the PWD builds their self-esteem. Therefore, mealtime presents an excellent opportunity to use strategies such as praising or giving compliments because they can promote the PWD's self esteem and sense of self.

While the previously discussed properties have been more specific to use in a single stage of dementia, working together was identified by 90%. In the sub-sample, dyads used strategies to help the PWD to gain a sense of independence; despite the fact the caregivers were mostly responsible for planning and preparing the meal. In the early and middle stages of dementia, the strategies the dyads used involved the PWD working as a "team" or in tandem with the caregiver as the PWDs were still able to participate in mealtime activities. In contrast, by the later stages, the dyads evolved their strategies to encourage the PWD to participate on a limited basis because reciprocity of working in a team was virtually non existent. I suspect that using strategies like modifying appliances for simple use and "training" the PWD to participate in mealtime preparation help the PWD to feel like they are making a contribution. In fact, Manthorpe and Watson (2003) support having the PWD living in the long term care settin involved in mealtime tasks such as preparation, cooking and washing-up because they suggest that their participation in these activities may stimulate their appetite or at least create an interest in the food. Manthorpe and Watson also point out that keeping the PWD 'safe' from the potential harms of mealtime

involvement may actually be isolating and disempowering to them. Therefore, encouraging participation and working together is vital throughout dementia's progression.

The final property in this category was taking a sensitive approach to suggestions for the PWD, which includes strategies that can be used in all stages dementia. For example, CG23 phrased mealtime related questions so that PWD23 not only had the decision making power but also so the question had her suggestion embedded within it. Similarly, CG5 used physical cues to help his mother know she had made a mistake. By the later stages of dementia, behaviours such as preparing "bizarre" appetizers or "spit[ting]" food into a Kleenex, involved the caregivers using strategies such as forgiving and not dwelling on the actions of the PWD. In all of the cases, the caregivers used strategies that were sensitive to their spouse and parent's feelings while being cognizant of the PWD's sense of personhood.

It is interesting to note however, that by the late stages dementia, caregivers noted the child-like behaviour of the PWD. For example, CG1 stated that "If he (PWD1) wants to eat it with his fingers, then, let him enjoy it. He is [the] same like the children." CG17 supported this statement and also told that "I find that he snacks more through the day... he's like a child sometimes." This caregiver also added that, "he's an adult and I'm treating him like a child. But he doesn't see it that way... you know." Given that these caregivers have identified that they may view their PWD's behaviour as child-like, strategies related to taking a sensitive approach to suggestions for the PWD in the later stages may be even more significant than in the earlier stages. Hughes, Hope, Reader & Rice (2002) warn that it is essential that informal caregivers use language that is empathetic when speaking with the PWD in order to avoid talking down to them (infantilization) and making them feel that they are a little child. Therefore, in relation to

infantilization, this strategy might prove to have even greater significance in the later stages as identified in this sub-sample.

After reviewing all of the properties and individual strategies that were present in strategies used to promote a sense of self, I was able to further define this category according to stage of dementia. The following provides a definition of the category strategies used to promote a sense of self according to the stage of dementia.

Early stage dementia definition. Pragmatic strategies identified by the caregiver and PWD that are used to maintain a sense of purpose during mealtime time includes: participating and working together in some aspect of the meal preparation or clean up as well as maintaining a sense of control.

Middle stage dementia definition. Pragmatic strategies used by the caregiver and PWD to promote a sense of self for the PWD include: working in cooperation to maintain and promote abilities and taking a sensitive approach to suggestions.

Late stage dementia definition. Pragmatic strategies used by the caregiver to promote the sense of self for the PWD during mealtime include: keeping a connection to share with each other, identifying and focusing on the strengths and abilities of the PWD, and forgiving mealtime mistakes made by the PWD. The onus is on the caregiver to facilitate the promotion of sense of self with their spouse or parent.

Strategies used to minimize safety risks. The category, strategies used to minimize safety risks, had four related properties with strategies that spanned the three stages of dementia but were mostly concentrated in the middle to late stages of dementia. The first property, accepting limitations and changing practices was identified across all of the stages, and the resulting strategies were employed by 50% of the dyads. It is reasonable that different safety issues will

present themselves at different times, given the changes in cognitive ability as dementia progresses as described by Reisberg and Franssen (1999). For example, PWD5 had significant memory difficulties, and therefore, even in early stage dementia, she had decided that she would not use the stove. The same strategy was used in the later stages by dyad 13 and 22, as these PWDs had accepted their limitations and no longer used the stove. Strategies in this property are supported by those listed in Lach and Chang's (2007) work which describes the facilitators, barriers and management strategies for creating a safer home environment for PWDs. In fact, Lach and Chang identify that being aware of potential and actual problems related to safety is a facilitator to creating a safer home environment. This supports the dyads in the sub-sample who identified that they had to change their practices as a result of recognizing the behavioural changes associated with dementia and the safety concerns that they presented.

While the property of accepting limitations was used across the stages, modifying appliances was more specifically used by dyads in the middle and later stages of dementia (30% of dyads). Physically altering appliances such as "tethering the stove" to the wall like in dyad 23 or placing a "piece of red tape on the on/off switch" on the stove like in dyad 19 were used to prevent accidents. These strategies are practical and congruent with those presented in Lach and Chang (2007) who suggest home environment modifications such as environmental cues (e.g. red tape) and safety equipment (tether) are reasonable strategies to employ.

Another property identified in this category was the removing of dangerous items and is specific to the late stage (20% of dyads). In this stage, it was reasonable that taking a proactive approach to safety was best. People with more advanced dementia can be unaware of their surroundings and have significant memory impairment, therefore in this stage removing the danger is an appropriate decision (Reisberg & Franzen, 1999). Perhaps, this type of strategy can

seem like a paternalistic style of caregiving, by taking away the tools that allow the PWD to participate in the meal preparation. However, according to Reisberg's staging tool (1999) cooking and using heating elements may be going beyond the capabilities of the PWD if used alone and therefore, careful assessment and strategies are necessary to ensure safety at mealtime.

The last property, teaching and reinforcing, again, was used solely in the late stages by half of these dyads. From the sub-sample, I gathered that PWDs in the early to middle stages were able to mutually agree on safety measures and strategies as listed above. For example, in dyad 23, the mother and daughter mutually agreed that they would "tether the stove to the wall." However, as the dementia progressed in this sub-sample, it was apparent that the onus was on the caregivers to provide safety strategies, such as removing the potential danger, or taking sole responsibility for using heating elements. Therefore, it was fitting that the strategies used in this property, were again, the caregiver reminding the PWD not to touch the stove or instructing the PWD how to use the modified microwave. At this late stage, the mutuality of deciding on strategies to minimize safety risks is virtually non existent and therefore taking the educational approach of teaching and reinforcing was necessary.

After reviewing all of the properties and individual strategies that were present in strategies used for minimizing safety risks, I was able to further define this category according to stage of dementia. The following provides a definition of the category strategies used for minimizing safety risks according to the stage of dementia.

Early & middle stage dementia definition. Pragmatic strategies that promote physical safety for the person with dementia related to food preparation. This is a mutual process, where the caregiver and the PWD design the strategies; however the PWD must agree to enact them.

Late stage dementia definition. Pragmatic strategies used by the caregiver that promote physical safety for the PWD related to food preparation including teaching and reinforcing, accepting the limitations of the PWD as well as removing dangerous elements.

Strategies to promote the caregiver's sense of self. The final category, strategies to promote caregiver sense of self, was diverse in nature, with not as much overlap in the properties and strategies identified by the caregivers as shown in table 11. Indeed, caregivers spoke of many personal strategies that they used to cope with dementia at mealtimes. I suggest that their stated strategies should not be analyzed according to stage. In fact, I believe that coping strategies should be considered useful for all stages of dementia, as caregivers in the community may be as varied as those in the sub-sample. For example, the strategy of channeling stress as identified in the early and middle stages in the sub-sample may be useful for other caregivers experiencing late stage dementia, even though not identified in this specific stage.

Coon, Rupert, Solano, Mausbach, Kraemer and Arguëlles et al. (2004) state that research that has focused on the physical and psychological impact of caregiving for PWDs in the Caucasian population. Therefore, strategies that are useful for other cultures may not be identified. For example, Coon et al. found a significant difference in the frequency of religious coping by female Latina caregivers of PWDs, when compared to Caucasians. Similarly, in a related study, Haley, Gitlin, Wisniewski, Feeney Mahoney, Coon and Winter et al. (2004) found that like the female Latina caregivers, African American caregivers used religious practices as a psychosocial coping strategy more frequently than Caucasians. These two examples demonstrate that caregivers may be unique and identify with different coping strategies to deal with the progressive dementia behaviours. Therefore, caregiving coping strategies are unique to the people who use them, and should not be categorized according to stage of dementia.

Sub-questions

2) How do the strategies and the reasons behind their use compare between the dyads of a person with advancing dementia and their spousal caregiver and the dyads of a person with advancing dementia and their adult child caregiver?

Overall, both the spousal (S) and adult child (AC) caregiver dyads identified with the majority of the properties identified in the four categories, with the exception strategies used for caregivers. Only the properties of preparing an appetizing meal and adapting the setting showed an overall difference in the strategies that the caregivers identified. As shown in table 8, it was apparent that the AC caregivers in the late stages of dementia use strategies of preparing an appetizing meal and adapting the setting. Both of these caregivers identified that their parents still had good appetites and had the same preferences as themselves, and therefore, preparing an appetizing meal may not have been an issue that required special strategizing related to changing dementia behaviour. Similarly, these caregivers did not give an example or explain how they adapted the setting to enhance the dining experience. Again, PWD22 and PWD13 did not display any behaviours that require any special attention to creating an atmosphere conducive to coaxing them to eat; however the caregivers just may not have recognized or expressed strategies that they were using.

While there were no great differences in the strategies that were identified between the AC and S caregivers, both CG23 and CG13 (daughters) addressed reasons for engaging in mealtime strategies with their parents. I interpreted what these two daughters described about their caregiving as an 'obligation out of love' for their parents. This 'obligation out of love' was exemplified by CG23 when she stated that, "Um, well I think that what I do, I do out of love for her." CG13 also explained that:

CG13: I find that she doesn't talk as much as she used to. And ... like me knowing what's going to happen really sometimes sets me back. So I try, like I say, to keep it going as long as I possibly can, at mealtimes.

Interviewer: Can you tell me why?

CG13: Because I love her.

In contrast, I got the sense that all of the S caregivers engaged in mealtime strategies out of love for their husband or wife, but they did not explicitly state this.

As described above, there were some minimal differences in the strategies and reasoning used by the different types of caregiver dyads. However, the secondary analysis demonstrated that the context in which the caregivers engaged in mealtimes with their PWD had the greatest difference between the AC and S types. One main difference in the caregiver context was that the adult children in the sub-sample seemed to have more responsibilities outside of the dyad relationship. Unlike all of the S caregivers whom were retired, 75% of the AC caregivers were either still working or had other child care responsibilities. Therefore, while the S caregivers could focus on their relationship and needs of the PWD during mealtimes, the AC had competing priorities which may have altered their experience.

Another difference in the caregiving context was that the adult children in the sub-sample were at a different stage of their life when compared to the retired S caregivers. In general, the married couples had 'grown old together' and their lives had evolved as a couple. Therefore, their mealtimes had been shared together over their married life. In contrast, the adult children were not involved in sharing a meal with their parent on such a frequent basis as S caregivers until they received the dementia diagnosis and required assistance. It is as if the adult children had to reinsert themselves into the mealtime experience with their parent.

Davies and Gregory (2007) support that dyads of PWDs and their spousal caregivers have a commitment to each other and their marital relationship, which is shaped by historical and contextual factors. Davies and Gregory explain that couples living with dementia are indeed 'living-in-relationship', which I feel is different from the relationship of the AC and their parent with dementia. It is reasonable that adult children do not share the same history and intimacies as do the married couples during mealtimes. In fact, the contextual differences in the caregiver relationship with the PWD helped me to understand the concept of attachment in older adult life. I felt that the rich history and relationship of the S caregiver dyads shared together during mealtimes gave meaning to the "secure base" and "proximity keeping" concepts as cited in Cookman (2005). As I understand now, the intimate relationship of the S dyads gave the caregiver and PWD the opportunity to experience each other as an attachment figure during mealtimes. The mealtime experience was an occasion where they remained close to each other and shared together.

Overall, this chapter provided an in-depth analysis of the findings in the secondary analysis. I described my interpretation of the findings in relation to my research question, sub-questions and relevant literature. The following chapter will provide a discussion of the pertinent issues presented earlier.

Chapter Six: Discussion

Chapter six will provide a discussion about the findings of the secondary analysis. This chapter explores my underlying assumptions, strategies identified in the foundational study, theoretical guidance and the concept of reciprocity in caregiving.

Underlying Assumptions

In the methods chapter, I discussed the underlying assumptions that I had when I began the secondary analysis. To briefly summarize, I believed that: 1) mealtimes for a person with dementia (PWD) in the late stages required additional planning and strategies for the caregivers, 2) mealtimes for a PWD in the late stages meant patience and understanding, 3) mealtimes for a PWD with early or middle stage dementia meant a chance for socialization, 4) mealtimes for caregiver dyads meant a time to be together.

The secondary analysis provided an opportunity to examine the assumptions I held prior to engaging in the research. My first assumption as outlined above that PWDs required more planning and strategies in the later was demonstrated in the sub-sample data, by the evolving strategies that the caregivers were using by this stage. The caregiver dyads in the late stages developed strategies that involved coaxing the PWD to eat, as well as provided additional safety strategies. Also, compared to all of the dyads in the sub-sample, PWD1's challenging mealtime behaviours were beyond what other dyads had described. In fact, dyad 1 identified the most unique strategies used to facilitate eating, when compared to other dyads. In particular, at the time of the interview, PWD1 was the only PWD in the sub-sample who had a poor appetite and demonstrated behaviour such as wandering away from the table with no apparent purpose.

My third assumption as outlined above, that mealtimes provided a chance for socialization between the dyad members was demonstrated by the mealtime experiences

described by dyads in the early to middle stages. For example, dyad 12 used opportunities to eat out as a chance to not only socialize with each other, but feel a "social connection" to the community. In this case, food was just the "excuse" to get together with friends. In addition, dyad 6 used mealtime as the chance to reminiscence about the lives of their extended family, by "reading cards" sent to them by family members. Overall, my assumptions about the chance for socialization were realized however, the extent to which dyads could "emotionally connect" as described in Keller et al. (2007) was additional learning for me. My experience as a Registered Nurse had been with people whose life stories were largely unknown to me. Therefore, analyzing the data which described the social connection felt during mealtimes for dyads that had lived together for up to 60 years was powerful and went far beyond my understanding and assumptions related to this phenomenon.

My fourth assumption as outlined above, that meals provided an opportunity to be together was exemplified by the description of the mealtime experiences throughout the data set. In fact, in dyad 5 and dyad 23, the PWD and caregiver lived separately, and therefore mealtime served as a chance for them to be together. In addition, those dyads that used the strategy of eating apart, engaged in day programs, and other separate pleasure activities used the mealtimes where they did eat together as a chance to connect and be together.

Mealtime Strategies in the Foundational Study

As previously discussed, I identified four categories with related mealtime strategies in the secondary analysis. Afterward, I compared the changes in PWDs eating behaviours in the sub-sample to that in the foundational study by Keller et al. (2007). Silverman (2005) advises that it is important for the researcher to address previously reviewed literature. After reviewing this article, I decided that, I would compare the 'eating conduct changes' in Keller et al.'s work

with the changes in mealtime behaviour that were described by the participants in the secondary analysis. I also thought that the ‘adaptations trialed by family members’ in Keller et al.’s study would compare to the mealtime strategies explained by the participants in the secondary analysis. Given the comparisons that I used, I concluded that only nine ‘eating conduct changes’ and the identified adaptations trialed by families listed by Keller et al. were congruent with the findings of the secondary analysis. These congruencies are summarized in table 13 below. In addition to the congruencies, there were also four similar behavioural changes identified in both Keller et al.’s study and the secondary analysis where the strategies used to cope with these behavioural changes to eating conduct were different when comparing the adaptation listed in Keller et al.’s work to the secondary analysis. These differences are summarized in the table 14 below.

Table 13
Congruency of Identified Strategies between Keller et al.’s Foundational (2007) Study and the Secondary Analysis

‘Eating Conduct Changes’ Common to both Keller et al.’s (2007) study and the Secondary Analysis	Adaptations Trialed by Families and Strategies Common to both Keller et al.’s study and the Secondary Analysis
Increased pickiness	Ask about food preferences
Dissecting food	Provide single, plain foods
Refusing food	Provide favourite food, ask for preferences
Cooking difficulty	Use convenience foods when alone
Poor appetite	Be alert to know when to change food items
Eats too slowly	Provide time to eat at own pace
Messiness	Do not single out
Rituals/Routines may be lost or may increase rigidity	Providing meals and snacks at consistent times
Concern with nutrition, adequate intake	Promote balanced meals by preparing plates

Note. Adapted from Keller et al. (2007)

Table 14

Comparison of the Different Identified Strategies between Keller et al.'s (2007) Foundational Study and the Secondary Analysis

'Eating Conduct Changes' Common to both Keller et al.'s (2007) study and the Secondary Analysis	'Adaptations Tried by Families' in Keller et al.'s study	Strategies Identified in the Secondary Analysis
Using hands to eat	Provide "natural" finger foods and join in eating with hands	Letting the PWD enjoy the meal with his hands (without necessarily providing finger food)
Choosing food from a menu	Provide with simpler choices	Dining at familiar restaurants
Routines may be lost or may increase rigidity	Identify on a white-board the next eating occasion, prepare for meal by reminding of a few minutes before and setting visual cues	Provide meals and snacks when hungry
Inability to learn from mistakes	Be patient and realize that the disease makes it difficult to learn and remember	Do not constantly correct the PWD

Note. From Keller et al. (2007).

In addition to the adaptations trialed by families identified in Keller et al.'s (2007) study, six general themes that were previously described, gave meaning to the mealtime experience for families living in the community. Of these six themes, three overarching congruencies were found when compared to the categories that emerged in the secondary analysis. First, the theme 'eating together is social' explored by Keller et al. was evident in the sub-sample in the secondary analysis. Keller et al. found that "making the meal ritual an important event for the people with dementia to stay emotionally connected to the family" (p. 437). Similar to this finding, the data in the secondary analysis showed that mealtimes were an opportunity to provide companionship for each other and a chance to engage in quality time spent together. Interestingly, this finding is supported by Hopper, Cleary, Baumack and Fragomeni (2007), who support that mealtimes serve as a natural opportunity for conversation and participation between persons with dementia and their institutional caregivers. However, I think the opportunity for the chance to stay "emotionally connected" in the dyad fades as dementia advances and the actual meal became more about strategies to facilitate eating of the food, like in dyad 1 or dyad 22. Overall, eating together can be social; however, caregivers can find it necessary to eat apart from the PWD at certain times in order to cope, as identified in the secondary analysis.

Along with the theme, 'eating together is social,' 'the need to simplify' also showed similarities between the foundational study (Keller et al., 2007) and the secondary analysis. Keller et al. explained that the need to simplify was a method by which caregivers could relieve their strain and promote independence for the PWD. There were several ways in which families simplified mealtimes, which included meal preparation, the dinner party size, the type of food served and the timing of eating in the secondary analysis.

In addition to these two overarching themes presented in Keller et al.'s (2007), 'stepping in' was also in common with the strategies described in the secondary analysis. The strategies that centered on the caregiver providing assistance to the PWD in the secondary analysis were similar to those that represented this theme in the foundational study. Keller et al. suggested that caregivers wanted to give the PWD as much independence as possible before they 'stepped in' and provided assistance. Strategies in the secondary analysis that were included in the working together property complimented those presented in Keller et al.'s 'stepping in' theme. In both cases, the caregiver was assuming greater responsibility for mealtimes. However, they were cognizant of maintaining the abilities and sense of self of the PWD. Overall, the themes that were presented in Keller et al.'s foundational study were similar to three of the categories identified in the secondary analysis. Contrastingly, the secondary analysis showed the caregivers identified strategies that were helpful to alleviate their own stresses and frustrations during the mealtime which were not elucidated in Keller et al.'s work. Therefore, the secondary analysis added strategies that were helpful to the conduct of caregivers in the community setting to the existing body of literature.

Theoretical Guidance

As stated earlier, I used the concept of personhood, the development of which is often accredited to Kitwood (1997), to guide the secondary analysis. Specifically, I used the concept of 'personhood' to acknowledge and recognize the contributions of the PWD while I was analyzing the interview transcripts. I approached the data set knowing that the voice of the PWD should be equally heard and valued as I was discovering the strategies that were used by the dyads in the sub-sample. For example, I was able to use this concept to guide the analysis in the interview of dyad 1, where the caregiver had to explain most of their strategies due to the communication

difficulties of the PWD. CG1 was able to translate for the PWD1 that he did indeed 'eat better' with more people during mealtimes. This is only one example of how the use of 'personhood' helped to acknowledge the voice of the PWD in my findings. Using the personhood movement as a guide enabled me to recognize the importance of hearing the voice of all the PWDs within the sub-sample. Therefore, according to the guide of 'personhood' the strategies of the PWDs were included as findings in my secondary analysis in order to give this vulnerable population a voice. While recognizing the voice of the PWD served as the sole way I used the personhood movement, I could have used this concept more comprehensively. Kitwood (1997) states that, "personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 9). In particular, Kitwood and Bredin (1992) support that "persons exist in relationship; interdependence is a necessary condition of being human" (p 284). Given the underlying assumptions that I held that mealtimes are social during the early to middle stages of dementia, I could have applied these perspectives of Kitwood and Bredin during the analysis of the data. It was apparent in the data that eating was indeed a social process, and that the notion of mealtimes in the context of the 'relationship' cannot be ignored. Therefore, if this secondary analysis were to be repeated, I would use the tenets of the personhood movement to a greater extent.

While I stated that using more facets of the personhood movement in the secondary analysis may have been beneficial, I believe that a relationship-centred care approach could have also complimented this research subject. Indeed, it is noted by Dewing (2008), that nurses may be skeptical about using theories of person-centredness and prefer a more 'practical and user friendly' approach to care such as relationship-centred care frameworks, for example: the Senses Framework presented in Nolan, Davies, Brown, Keady and Nolan's (2004) work. Therefore,

since it has been identified that nurses may be skeptical of person-centredness, I suggest that it is critical to not disregard complimentary approaches to guide mealtime research such as relationship centredness. In fact, if professionals identify with relationship-centered care, then they may in turn have a greater appreciation of the results and implications from research which includes guidance from this approach.

In addition to personhood, I was also guided by the concept of attachment as it applies to older adults in the secondary analysis. The two concepts of secure base effect and proximity keeping as described in the third chapter were used to help me to understand the bond between the PWDs and their caregivers during the mealtime experience. In the third chapter I also made reference to Wright et al.'s (1995) assertion that attachment behaviour was evident in the care that a child gave to a parent who was chronically ill with Alzheimer's disease. However, I found that in addition to the adult children, the spousal caregivers also showed attachment behaviour during the mealtimes in the sub-sample. As I stated earlier, some of the couples had lived together for up to 60 years at the time they were interviewed and had experienced many mealtimes together. I was able to use the concepts of secure base and proximity keeping to help me to understand the connection and the 'togetherness' of the spousal and adult child caregivers during the mealtimes. I think that without having the guidance of these principles, the significance of the connection and 'togetherness' may not have been realized during the data analysis.

Reciprocity in Caregiving

The concept of reciprocity, or lack thereof, appeared in the data set. First, reciprocity is described by Wentowski (1981) as a balanced and equivalent exchange of content in a relationship. In the data, this concept could be applied to the adult child caregiver dyads. King,

Collins and Liken (1995) described that child caregivers feel that they have to or have the opportunity to "pay back" or reciprocate the care that their parent gave them as a child. However, this interpretation of reciprocity focuses on the entirety of the exchanges throughout the dyads' lives together, and largely ignores the immediate relationship exchange. The decreased communication and meal preparation abilities that were evident in the late stage PWDs in the sub-sample would have made their reciprocal relationship with their caregiver difficult to obtain by Wentowski's definition. Therefore, the notion of reciprocity in caregiving strategies may be an area of further inquiry in the mealtime context.

In particular, the experience of reciprocity for adult male children may be an area of interest. As described earlier, CG22 used the example of when he would invite his mother to help chop a single vegetable during meal preparation, so that it made him feel like "less of a galley slave." After reading this quotation, I inferred that by referring to himself as a "galley slave" the reciprocity in the relationship was lost. I wondered at what point that this caregiver realized that he was not engaging in an immediate reciprocal relationship but rather "paying back" the PWD for incidences in the past relationship. Additionally, CG5 described that he did not feel the need for conversation during his meals with his mother. In fact, both male adult children acknowledged partners that they had outside of the dyadic relationship that they could engage in a reciprocal relationship during mealtimes. Similarly, Neufeld and Harrison (1998) found that husband caregivers formed relationships with women in order to engage in social activity. While Neufeld and Harrison's findings are specific to the spousal relationship, it demonstrates the need of some male caregivers to have social reciprocity in their life outside of the dyad relationship. As mentioned earlier, adult children had in the sub-sample had to 'reinsert' themselves into the dining experience with their parents and perhaps seeking out social reciprocity outside of the

dyad represents one facet in which this context was altered.

In summary, this chapter addressed how the results of the secondary analysis informed my underlying assumptions as well as how the foundational work of Keller et al. (2007) related to the secondary analysis. In addition, I discussed the importance of the theoretical guidance provided by the concepts of personhood and attachment as well as the notion of reciprocity in caregiving. The subsequent and final chapter will address the implications of this secondary analysis as well as my concluding thoughts on this thesis project.

Chapter Seven: Implications & Conclusions

Chapter seven addresses the potential implications resulting from the findings of the secondary analysis. The implications of this secondary analysis will be explored through describing research opportunities, practical mealtime strategies for a person with dementia (PWD) and their caregivers living in the community and enhancing professional practice. I will conclude with a summary and my concluding thoughts of the secondary analysis.

Implications

Research opportunities. The following provides examples of possible research opportunities that would add to the existing body of literature on mealtime strategies for the dyads of PWD and their caregivers. The secondary analysis demonstrated that mealtime does require dyads to adapt to and create strategies to cope with dementia behaviours. Therefore, research inquiry that explores mealtime strategies for different populations of PWDs living in the community would be beneficial. This secondary analysis focused on the mealtime strategies for PWDs who had the support of informal caregivers in the community. Indeed, research that explores the mealtime strategies used by PWDs living alone in the community may prove to be an interesting inquiry given the presence of the caregiver in the secondary analysis. If future inquiry were to elucidate the mealtime strategies of this population, an interesting sub-focus may be to discover their opportunities for social dining in the community in order to learn their strategies to stay connected with others.

Non-Caucasian PWDs are another population that could be featured in research inquiry that uncovers mealtime strategies in addition to those living alone in the community. As discussed earlier, dementia research has mainly focused on Caucasian populations. The sub-sample in the secondary analysis did not address this limitation in the literature. Therefore future

research that focuses on discovering the mealtime strategies for a variety of cultures may not only give a greater insight to the mealtime experience in dementia but additional strategies that could be preferred by different cultural groups.

In addition to the research opportunities which could elucidate the mealtime strategies of different populations of PWDs, there are implications for the use of secondary analysis. These implications might include understanding the tacit knowledge of the primary researcher and the number of individuals collecting data in the primary study. First, Thorne's (1996) caution that primary researchers may have tacit knowledge or understanding was realized during this thesis process. Having previous experience with interviewing, I missed being able to engage in the interview process and take in the participants' reactions to questions and body language. While the dyad composites and narrative notes gave me additional understanding to the context of the interviews, I did not feel that I had a complete knowledge of the process. Therefore, the implication for developing a relationship with the primary researcher or research team is imperative in secondary analysis, especially where additional notes and reflections are not available. It is important that the secondary analyst be able to ask questions of the primary researcher or team if they want to more fully explore the data set. Second, an implication for the secondary analyst is to be cognizant of the number of individuals whom have collected interview data in the primary study. I analyzed interview transcripts collected from five different interviewers and I found that they had unique interviewing styles that explored the phenomenon of interest at varying levels of depth. Therefore, it is important that secondary analysts be aware that not all of the available data will contribute to the secondary study's intent to the same degree.

Practical mealtime strategies. The following provides examples of implications for PWD and their caregiver living in the community. First, it is important to recognize that as dementia advances, mealtimes can become a source of stress as demonstrated by the late stage dyads in the secondary analysis. An important implication for caregivers in all stages is need to self monitor their stress level, as mealtime is just one aspect of care that they may be responsible for providing. Education and counseling that focuses on mealtime challenges, successes and strategies may help to inform the caregiver about this aspect of care they provide and thus prepare them for the importance of self monitoring. In particular, coping strategies need to be acknowledged by the caregiver, so that they know they are just not 'doing for' the PWD but rather paying attention to themselves. Seeking the advice from local Alzheimer disease support groups may be useful for exchanging and learning effective mealtime strategies.

Another important implication is that the strategies used by the dyads to cope with the progressive mealtime behaviours associated with dementia were varied in the secondary analysis. Therefore, dyads should not feel that they need to adhere to prescriptive strategies for each stage of dementia if they do not suit their individual style of caregiving or of equal importance, the needs of the PWD. The strategies that were identified in the secondary analysis can serve as important starting point for the informal caregivers and PWDs living in the community. The identified strategies can be adapted to accommodate the changing mealtime behaviours of the PWD.

An additional implication for caregivers living in the community is using strategies that involve them eating separately from the PWD. This type of strategy may offer the caregiver a break from the lack of social reciprocity experienced when PWD is no longer participating in mealtime conversation and/or engagement. Eating separately from the PWD may require the

assistance of personal care workers or participation day programs. In addition, the caregiver may need reassurance from professional staff to act upon this strategy, if they have habitually shared meals with the PWD.

Enhancing professional practice. The following provides examples of implications to enhance professional practice. First, the findings of the secondary analysis may serve to inform professionals of the strategies that can be used to facilitate eating, promote a sense of self, minimize safety risks and acknowledge caregiver coping strategies in the community. Professionals who work with dyads experiencing dementia in the community may be able to incorporate the strategies identified in this secondary analysis into their educational materials or counseling.

Another implication for professionals in long term care homes is to investigate the strategies that the dyads have been using upon the PWD's transition into this living situation. Three PWDs in the sub-sample transitioned into either nursing homes or assisted living homes after the first year interviews were completed. Therefore, the need for assessment and incorporation of the strategies that facilitated eating or promoted their sense of self for the PWD may be useful to inform the professional staff on how to more easily facilitate the PWD's transition to an unfamiliar mealtime setting.

A final implication for professional practice is that mealtime can serve as an opportunity for the PWD and the caregiver to socially engage with each other. Establishing a rapport or simple connection to the PWD is important for staff that may enter their home in the community and engage in the mealtime experience. Staff needs to be aware that mealtime activities should not be seen as tasks, rather an opportunity to connect with the PWD and engage in a socially meaningful experience for both parties.

Overall, these implications resulted from the findings of the secondary analysis. They could be considered by individuals in the community, LTC institutional settings, and the larger research community.

Concluding Thoughts

The description of the findings from the secondary analysis showed that PWDs and their primary caregiver living in the community did in fact engage in mealtime strategies that served to meet their needs as a dyad. In particular, the dyads in the sub-sample used strategies that not only addressed the changing physical, social and safety concerns of the PWD but also the needs of the primary caregiver in the mealtime context. The dyads identified strategies that could be used to facilitate eating, minimize safety risks, and promote both a sense of self for the PWD and sense of self for the caregiver. In general, the strategies used by the dyads demonstrated that as dementia progressed from the early to late stage there was a shift towards greater caregiver involvement and responsibility during the mealtime experience. However, even though the caregivers were taking on more mealtime responsibilities, the voice and experience of the PWD was not overshadowed in the identification of the strategies used by the dyads. Indeed, in every dyad in the sub-sample, both members were integral in explicating and sharing their meaning of mealtimes.

As a secondary analyst, I was captivated by the rich explanation the dyads provided of their mealtime experiences. I was inspired by the capacity and commitment of the dyads' members to continually strategize and participate in ways to enrich their mealtime experience in the face of a progressive and irreversible disease whilst living in the community. It is my ultimate hope that readers of this secondary analysis will gain an appreciation of the strategies

that PWDs and their primary caregivers use to not only satisfy their physical hunger but nourish their souls through the opportunity that mealtime presents for social connection.

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Appendix A

Ethics Approval Notices

McMaster University Research Ethics Board (MREB)

c/o Office of Research Services, MREB Secretariat, GH-306, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN

PARTICIPANTS IN RESEARCH

[illegible]

P:/ethics/reviewers/forms/certificate.frm

ACTING CHAIR

University of Guelph Ethics Approval Notice

----- Forwarded message from Sandy Auld <sauld@uoguelph.ca> -----

Date: Wed, 24 Nov 2004 16:05:43 -0500

From: Sandy Auld <sauld@uoguelph.ca>

Reply-To: Sandy Auld <sauld@uoguelph.ca>

Subject: ethics approval REB#04NV007

To: hkeller@uoguelph.ca

University Centre, Room 437, Guelph, Ontario, N1G 2W1

MEMO

DATE: November 24, 2004

TO: H. Keller

CC: S. Dupuis; L. Martin

FROM: S. Auld

SUBJECT: REB# 04NV007

TITLE: Eating Together in Families with Dementia: A longitudinal analysis.

Thank you for submitting the changes to your Research Ethics protocol REB#

DECISION: Approved with submitted changes.

This project has been approved for a period of one year and may be extended upon request. The study may now proceed. The hard copy of your ethics certificate will be mailed to you.

Please note that 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.

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 Principal Investigator, 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 (TCPS) requires that ongoing research be monitored. A Final Report is required for all projects. Researchers with projects lasting more than one year are required to submit an Annual Report. The Research Ethics Officer (REO) will contact you when this form is required.

All forms are available on the Office of Research website.

<http://www.uoguelph.ca/research/forms/index.shtml>

Please quote your REB file number on all future correspondence. If you have any questions, please do not hesitate to contact:

Sandy Auld

Research Ethics Officer

Office of Research

University Centre, Room 437

519-824-4120 X56606

----- End forwarded message -----

Heather H. Keller RD, PhD

Associate Professor

Department of Family Relations and Applied Nutrition

University of Guelph

Guelph, On

CANADA

Phone: 519-824-4120 ext 52544

Fax: 519-766-0691

N1G 2W1

University of Waterloo Ethics Approval Notice

Date: Thu, 2 Dec 2004 16:15:05 -0500

From: "Heather H. Keller" <hkeller@uoguelph.ca>

To: Gayle Edward <gaedward@uoguelph.ca>

Subject: Fwd: Full Ethics Clearance after provisional, comments (ORE # 11944)

----- Forwarded message from ORE Ethics Application System <OHRAC@uwaterloo.ca>

Date: Thu, 02 Dec 2004 15:29:10 -0500

From: ORE Ethics Application System <OHRAC@uwaterloo.ca>

Reply-To: ORE Ethics Application System <OHRAC@uwaterloo.ca>

Subject: Full Ethics Clearance after provisional, comments (ORE # 11944)

To: hkeller@uoguelph.ca, sldupuis@healthy.uwaterloo.ca,
lori@shalomvillage.on.ca

Dear Researcher:

The recommended revisions/additional information requested in the initial ethics review of your ORE application:

Title: Eating Together in Families with Dementia: A Longitudinal Analysis
ORE #: 11944

Principal/Co-Investigator: Heather Keller (hkeller@uoguelph.ca)

Principal/Co-Investigator: Sherry Dupuis (sldupuis@healthy.uwaterloo.ca)

Principal/Co-Investigator: Lori Shindel Martin (lori@shalomvillage.on.ca)

have been reviewed and are considered acceptable. As a result, your application now has received full ethics clearance. However, further revisions and/or additional information are required as outlined below.

A signed copy of the Notification of Full Ethics Clearance will be sent to the Principal Investigator or Faculty Supervisor in the case of student research.

ADDITIONAL REVISIONS OR ADDITIONAL INFORMATION:

FYI a copy of the Full Ethics Clearance Certificate is being sent, by mail, to both Heather and Sherry.

Revised materials should be provided within ten days to the Research Ethics Coordinator in the Office of Research in hard copy or by email to ohrac@admmail.uwaterloo.ca .

Note 1: This clearance is valid for four years from the date shown on the certificate and a new application must be submitted for on-going projects continuing beyond four years.

Note 2: This project must be conducted according to the application description and revised materials for which ethics clearance have been granted. All subsequent modifications to the protocol must receive prior ethics clearance through our office and must not begin until notification has been received.

Note 3: Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects. In addition, researchers must submit a Form 105 at the conclusion of the project if it continues for less than a year.

Note 4: Any events related to the procedures used that adversely affect participants must be reported immediately to the ORE using ORE Form 106.

Susanne Santi, M. Math.,
Manager, Research Ethics
Office of Research Ethics
NH 1027
519.888.4567 x7163
ssanti@uwaterloo.ca

----- End forwarded message -----

Appendix B

Consent Forms

SUMMARY OF STUDY PROCEDURE: *The "Eating Together" Study*

You are asked to participate in a research study conducted by **Heather Keller** at the University of Guelph [Department of Family Relations and Applied Human Nutrition], **Sherry Dupuis** at the University of Waterloo [Murray Alzheimer Research and Education Program (MAREP)], and **Lori Schindel Martin** at Ryerson University [School of Nursing]. This study is funded by the Alzheimer Society of Canada [ASC], and the Social Sciences and Humanities Research Council of Canada.

If you have any questions or concerns about this research, please contact:

Heather Keller at: 519 – 824 – 4120 ext. 52544.

PURPOSE OF THE STUDY:

We want to find out about eating situations and concerns of families experiencing dementia. We will talk with families, together and individually:

- 1) to find out about your experiences around mealtimes and their meanings to you,
- 2) to understand how these experiences affect your relationship, and
- 3) to identify which educational resources and strategies you have used, and how you prefer to address these nutrition issues.

PROCEDURES:

If you volunteer to participate in this study, we ask you to do the following:

1. participate in two interviews within approximately one month – one with your family member, and one by yourself. We expect that each interview will take about 60 - 90 minutes.
2. these interviews will be audio-taped so that we have a record of everything you say
3. talk with us again for follow-up interviews, annually for two years after that
4. review an annual summary of the combined results of all the interviews conducted so far
5. we will mail you a copy of the study results if you are interested in seeing them.

POTENTIAL RISKS AND DISCOMFORTS:

There are no known or anticipated risks to you by participating in this study.

POTENTIAL BENEFITS TO PARTICIPANTS and /or TO SOCIETY:

By helping us with this study, you will be able to share your eating and mealtime experiences and concerns with us. This may help you put things in perspective. Your stories combined with others will provide us with a picture of mealtime situations and issues, and will form the basis of developing educational materials and strategies that can be used by other families experiencing dementia and by health professionals dealing with such families.

PAYMENT FOR PARTICIPATION:

As a token of our appreciation we will give you, at the end of each year, a \$15 gift certificate.

CONFIDENTIALITY:

Every effort will be made to ensure confidentiality of any identifying information that we get in connection with this study. All data will be kept in locked cabinets in the research office at the University of Guelph and at the University of Waterloo. Any identifying information, like your name and address, will be removed from any written materials or from any quotes we may use in publications. Audio-tapes will be destroyed at the end of the study. Some of your specific comments may be used verbatim, but no one will be able to identify you.

PARTICIPATION AND WITHDRAWAL:

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may choose to remove your data from the study. You may also refuse to answer any questions you don't want to answer and still be in the study.

RIGHTS OF RESEARCH PARTICIPANTS:

You may withdraw your consent at any time and stop participating in the study without penalty or consequence. You are not waiving any legal claims, rights or remedies by being part of this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board [as well as through the University of Waterloo and McMaster University]. If you have questions regarding your rights as a research participant, contact:

Research Ethics Officer – **Sandy Auld**
University of Guelph
Reynolds Building, Room 203
Guelph, ON N1E 2W1

Telephone: 519-824-4120, ext. 56606
Email: sauld@uoguelph.ca
Fax: 519-821-5236

Consent form for interviews: "The Eating Together" Study

I have been told that:

- my participation in this study is entirely voluntary
- I will be talking together with my family member and an interviewer, and then alone with the interviewer, about eating and mealtimes
- I will be contacted for yearly interviews
- I may refuse to participate or withdraw from the study at any time with no effect on any care that I receive
- I can stop the interview at any time, and reschedule it if I choose
- all information is confidential:
 - it will not be used for any purpose other than this study
 - it will be stored in a locked filing cabinet at the research office
 - it will only be used by the researchers
- some of my comments may be used word for word, but people won't know they came from me
- the recordings will be destroyed at the end of the study
- this project has been approved by the University of Guelph Research Ethics Board. I may contact **Sandy Auld** to answer any questions I may have about my rights as a study participant (519-824-4120, ext. 56606)
- I have received a copy of this form for my records.

If I have any questions about this study, I may call:

Heather Keller, Project Leader, at 519 - 824 - 4120, ext. 52544

I consent to participate in this study, as indicated by signing below.

Print **Participant's** Name: _____ Date _____

Signature of Participant: _____

Print **Interviewer's** Name: _____ Date _____

Signature of Interviewer: _____

Appendix C

Interview Guidelines

“Eating Together” Study: Conversation Guide October 2005 [Yr1]

Setting the stage:

- Introduce topic area to be explored: e.g., “today we’re going to talk about “eating together” and what that means for you. We’re **not** going to be talking about specific foods or nutrition, or what you eat, but rather the “act of eating together”.

Main Questions:

- 1) **Tell me, about your mealtimes—about eating together.**
- 2) **Tell me about eating outside your home, e.g., going to restaurants**

Conversation extenders/probes

- has the mealtime experience changed as you’ve aged?
- what has been your most memorable meal recently?
- what is that like for you?

Issues to consider:

The meaning of mealtimes/eating out to the individual/family

- Child/parent dyad: Mealtimes with own family and with aging parent
- Spousal dyad: mealtime activity as a couple before dementia, when raising family etc.
- How mealtime is perceived as part of the family structure
- Consider different stances (gender, spousal, child, CG)

Changes that have occurred with dementia/ memory problems

- Stress/challenges
- New roles
- Positive aspects / changes
- Strategies developed to adapt to changes
- Mealtime influence on:
 - family relationship
 - CG relationship

Support accessed or needed around mealtimes and eating

- Where they go for support around mealtime/ food issues and dementia

“Eating Together” Study: Conversation Guide February 2, 2007 [Yr2]

a) before visiting the family:

- review composite portrait and key themes to refresh memory before visiting family.

b) with the family:

1. remind them about the study, its purpose; obtain informed consent; answer any questions.

2. Briefly describe how things were last time, and ask what has changed:

- with mealtimes: “so what are mealtimes like now?”
- with the disease: “so what changes are you noticing around mealtimes about the house, like using objects inappropriately, not following through?” [not just memory] What did they do last year that they are now not doing (e.g., setting table)? What prompted this (e.g., no longer knowing where cutlery goes)?
- “what other things have influenced changes?” e.g., CG characteristics, transit, etc.

3. *[Evolving life]*

Ask about:

- “making it work” vs “doing what you have to”. Where are they at now? Has this shifted for them as the disease has progressed?
- what are their challenges now
- what strategies are they using; what’s working or not.
- what support are they needing / using [family, community, PSW, emotional ...]

4. *[Being connected]* Being connected includes the dyad, extended family, friends, the community and the environment.

Ask about changes within the following 4 areas:

- **Face to face:** e.g., “Last year you ate [all your meals together]. How has that changed?”
- **Time:** e.g., “Last year you ate together primarily at supper, and the meal lasted x minutes. Has that changed in any way?”
- **Support:** e.g., “last year you talked about how meals with family were a way of feeling better, or to talk about things. How is that now?”
- **Belonging:** e.g., last year you were involved with [group]. Are you still doing that?

5. [Preserving Identity] Ask about changes around:

a) individual identity:

i. Autonomy

- Do you feel *respected*? How do you know?
- How are *decisions made* in your family?
- How is *trust* retained? *Is there trust*?
- Feeling of *control*

ii. Dignity: How does it work in this family? E.g.,

- are your choices respected?
- Remembering who they were, the importance of that
- having principles, i.e., what one does
- moral obligation, e.g., feeling duty or obligation/ not

iii. Roles

- Why role is important?
- How loss of role feels? What signals this?
- How do you deal with shifting/changing roles?

b) family identity: ask about changes around:

i. **sharing family culture** – reminiscing, having routines and rituals, setting an example, having roles. [traditions]

ii. **veiling reality** – trying to protect the family by obscuring / hiding/ ignoring / being oblivious.

- This may be intentional or not
- recognized or not
- accepted or denied.

c) **caring for yourself**: what do you do? [e.g., hobbies] Has this changed?

6. [experiencing life fully] Ask:

- What is life like for you now? What *one word/ phrase* would describe things?
- *what is central to their life now*? How do they see themselves, define themselves?
- How has it changed in the past year?
- How do mealtimes tie in? Do they reflect how life is lived? Do they mirror changes or experience?

- Can you see things getting better or worse? [future]

7. [eating out] Remind them of last year's frequency. How have things changed? Why?

Demographics:

- a) ask if living arrangements have changed
- b) check FAST staging
- c) for working CGs, ask if income has changed.

8. Thank you.

- Ask about gift certificate: 1st choice: Tim Horton's, Sears, Canadian Tire, Wal- Mart.
2nd choice: Zehr's or Swiss Chalet
- Mention that we plan to have a gathering in the spring. We'll invite them. We'll be in touch in about a year to do the final planned interviews.

Appendix D
Coding Framework

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
<i>Strategies Used To Facilitate Eating</i>	Maintaining a Routine	YES	YES	YES
	10/10= 100%	S 2/2	S 2/2	S 2/2
		AC 1/1	AC 1/1	AC 2/2
	Simplifying	YES	YES	YES
	9/10= 90%	S 2/2	S 2/2	S 1/2
		A/C 1/1	AC 1/1	AC 2/2
	Adapting the Setting	YES	YES	YES
	8/10 = 80%	S 2/2	S 2/2	S 1/2
		AC 1/1	AC 1/1	AC 0/2
	Preparing an Appetizing Meal	YES	YES	YES
	8/10= 80%	S 2/2	S 2/2	S 2/2
		AC 1/1	AC 1/1	AC 0/2

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
<i>Strategies Used to Promote a Sense of Self</i>	Eating Out	YES	YES	YES
	8/10= 80%	S 2/2	S 2/2	S 1/2
		AC 1/1	AC 1/1	AC 1/2
	Adapting to and Accommodating Changing Needs	YES	YES	YES
	7/10= 70%	S 1/2	S1/2	S 2/2
		AC 1/1	AC0/1	AC 2/2
	Gently Encouraging	NO	YES	YES
	4/10= 40%		S 1/2	S 2/2
			AC 0/1	AC1/2
	Working Together	YES	YES	YES
	8/10= 80%	S 2/2	S 2/2	S 0/2
		AC 1/1	AC 1/1	AC 2/2

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
	Taking a Sensitive Approach to Suggestions for PWD 7/10= 70%	YES S 0/2 AC 1/1	YES S 0/2 AC 1/1	YES S 2/2 AC 2/2
	Teaching 2/10=20%	NO	YES S 1/2 AC 1/1	NO
	Adapting to and Accommodating the Changing Needs of the PWD 1/10=10%	YES S 1/2 AC 0/1	NO	NO
	Praising 1/10=10%	NO	NO	YES S 1/2 AC 0/2

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
	Maintaining the PWD's Sense of Control 1/10= 10%	YES S 0/2 AC 0/1	NO	NO
<i>Strategies Used to Minimize Safety Risks</i>	Accepting the Limitations of the PWD 5/10=50%	YES S 0/2 AC 1/1	YES S 1/2 AC 1/1	YES S 0/2 AC 2/2
	Modifying 4/10= 40%	NO	YES S 1/2 AC 1/1	YES S 0/2 AC 2/2
	Teaching and Reinforcing 2/10=20%	NO	NO	YES S 1/2 AC 1/2
	Removing Danger 2/10=20%	NO	NO	YES S 0/2 AC 2/2

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
<i>Strategies to Promote the Caregiver's Sense of Self</i>	Eating Apart 5/10= 50%	YES S 0/2 AC 1/1	YES S 1/2 AC 1/1	YES S 0/2 AC 2/2
	Getting Outside Help 3/10= 30%	YES S 0/2 AC 1/1	NO	YES S 1/2 AC 1/1
	Accepting Changes Mealtime Behaviours 3/10= 30%	YES S 1/2 AC 0/1	NO	YES S 2/2 AC 0/1
	Accepting New Roles 3/10= 30%	YES S 0/2 AC 1/1	YES S 2/2 AC 0/2	NO
	Channeling Stress 2/10= 20%	YES S 1/2 AC 1/1	NO	NO

Category	Properties (Percentage of Total Dyads)	Early (Included Yes/No)	Middle (Included Yes/No)	Late (Included Yes/No)
	Having Patience 2/10= 20%	NO	NO	YES S 2/2 AC 0/2
	Recognizing Boundaries 2/10= 20%	YES S 1/2 AC 1/1	NO	NO
	Praying 1/10= 10%	NO	NO	YES S 1/2 AC 0/2
	Keeping up a "normal routine" 1/10= 10%	YES S 0/2 AC 1/1	NO	NO