COMMUNICATING WITH A FAMILY MEMBER WHO HAS COGNITIVE IMPAIRMENT:
A CAREGIVING FAMILY PERSPECTIVE

by

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ABSTRACT

Alzheimer disease (AD) and related dementias affect nearly one in thirteen Canadians over the age of 65. Difficulties in communicating are frequently cited as the greatest source of stress for individuals who have a diagnosis of dementia and their families. Despite the wide recognition that the family is affected by a relative’s diagnosis of dementia, there has been little research aimed at understanding the experience of the family as a unit. The purpose of this study is to gain insight into the family experience of communicating with a relative who has dementia.

This study used a qualitative single case study design, drawing on the theory of Symbolic Interactionism. Three members of one family participated in two individual interviews and a family interview. The family member who was experiencing symptoms associated with AD but whose diagnosis was referred to as “cognitive impairment” (CI), participated in one individual interview. Interviews were transcribed and the data was analyzed using constant comparative analysis.

The findings that emerged from the data indicate that the participating family approached communication with the intention of achieving three particular goals in their interactions. These goals were to include, protect, and bring happiness to their afflicted family member. Three strategies were identified as the primary strategies used to achieve these goals: interpreting, scripting, and translating. Further, the family was organized in such a way that members were positioned either as part of the ‘core’ of the family or on the ‘outskirts’ of the family. Family members that pursued and achieved the three goals in their interactions with the relative who has CI were considered to be part of the core while others who were not willing or capable of interacting in this way were positioned on the outskirts of the family.

Understanding the communication experience of the family as a unit offers a vital link to meet the needs of families dealing with the effects of CI. This knowledge will aid in formulating important new questions and insights for researchers and clinicians to provide the care and support necessary to promote the well-being of families affected by CI.
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CHAPTER 1
INTRODUCTION

In Canada, there are approximately 420,000 people with a diagnosis of dementia and it is estimated that this number will increase to 750,000 within the next 25 years (Alzheimer Society of Canada, 2005a). This disease primarily affects the older population with one in thirteen Canadians over the age of 65 years and one in three over the age of 85 years diagnosed with a form of dementia (Alzheimer Society of Canada, 2005a; Chertkow, 2008). Though there are various subtypes of dementia, each worthy of attention, the most common form of dementia is Alzheimer disease (AD), accounting for 64 percent of those diagnoses (Alzheimer Society of Canada, 2005a). As the population continues to age, these changing demographics and patterns of disease have significant implications for our health care system. In the financial realm, approximately 5.5 billion dollars are spent per year on persons with dementia in Canada (Alzheimer Society of Canada, 2005a). Half of those people afflicted with the disease reside in an institution, such as a long term care facility, for which there is often a long waitlist. The other half of this population lives in the community where care is primarily provided by family and friends. There is subsequently a growing population of family caregivers for relatives who have dementia (Alzheimer Society of Canada, 2005a; Canadian Study of Health and Aging Working Group, 1994).

Though the prevalence of the disease and the impact dementia has and will continue to have on Canada’s health care system are important factors to explore and understand, we are at risk of doing a major disservice to the understanding of the disease
and its effects. An understanding of the disease from a systems level without consideration of the experience and the impact of dementia at the most fundamental level, the level of the individual and the family, fails to recognize the human aspect that is so inherent in the experience of this disease. In this health care system that relies heavily on family members being willing and able to provide care and assistance to their relatives with dementia, it is essential that we seek to understand the experience of dementia at the family level in order to better support individuals with dementia and their caregiving families.

Though an individual may be given a diagnosis of dementia, the experience of dementia does not occur in social isolation. Cary Henderson (1998), a retired history professor diagnosed with AD, wrote in his published journal, “One thing about this [AD] is, it’s in the family and the family has not only me and my wife, but we have our children and the children have their spouses… it’s about a whole mess of people” (p.65). This “mess of people” experience the effects of the disease in many ways that go beyond the provision of caregiving tasks. The effects of the disease infiltrate into the daily life of the family, including the family communication.

Though various aspects of the family’s experience are worthy of understanding, the significance of communication within the family cannot be underestimated. Communication is a fundamental element of human relations (Byrne & Orange, 2005; Sabourin, 2006) and a person who has dementia inevitably experiences changes in their ability to communicate. Understanding how families experience the effects of these communication changes on the relations within the family and the family’s communication is an important way of shedding light on the experience of the family.
The purpose of this study is to contribute to the understanding of the family experience of communicating with a relative who has AD.

In this study, one member of the participating family has a diagnosis of "cognitive impairment" rather than AD. Because of the ambiguity that sometimes attends the diagnostic dialogue between family and health care professionals, and because the family met all the other relevant criteria for inclusion, the decision was made to include this family as the focus of the study and to respect the terminology they used as much as possible. Terminology issues will be discussed in Chapter 2.

Overview of the Study

In the preceding section, I have referred to the significance of dementia at the level of the health care system and at the level of the family. In Chapter Two, I review the literature that provides the foundation and informs the current understandings of the concept of family, cognitive impairment, family caregiving, and communication. The research questions of this study are presented at the end of this chapter. In Chapter Three, the theoretical underpinning of the research is described as well as the rationale for the method. The procedures pertaining to recruitment, data collection, and data analysis are also outlined. In Chapter Four, the findings of the study are presented and described. And finally, in Chapter Five, the significance of these findings is discussed and the chapter concludes with a discussion of the implications of the study.
CHAPTER 2
REVIEW OF THE LITERATURE

To fully appreciate the complexity of this field of study, four foci must be discussed. The literature pertaining to the elusiveness of family as a concept, the changing understandings of cognitive impairment (CI), the intricacies of family caregiving for persons who have CI, and finally communication in families with CI will be discussed. The knowledge offered in these areas provides the foundation upon which the research questions are asked and explored.

Family as a Concept

Family is an integral component of our daily lives yet the concept of family remains largely elusive. Families, once identified through blood relations, are becoming increasingly more complex with the common occurrence of divorce, remarriage, step-families, adoption, extended family units, and so on. Though most individuals and researchers agree that family is not synonymous with blood relations, there is considerable variation among the resulting definitions. As families are rarely asked to define family and state explicitly who is considered to be in their family, the challenges of conceptualizing family occurs primarily among researchers. In a review of the family literature, Allen, Blieszner, and Roberto (2000) acknowledged the difficulty of defining family with adequate precision for research purposes, claiming this task to be near impossible. The vagueness commonly associated with defining family is evident in Whall’s (1993) definition of family as “a self-identified group of two or more members...
who may or may not be related by bloodlines or law and whose association is characterized by special terms” (as cited in Astedt-Kurki, Paavilainen, & Lehti, 2001). Absent is an explanation or a description of what constitutes ‘special terms’. Further, some researchers claim that the family is the sum of its individual members (Friedman, 1998) whereas other researchers, claim that “families represent more than a set of individuals and a family is more than a sum of its individual members” (Astedt-Kurki, et al., 2001, p. 289). Johnson (2000) emphasizes choice in one’s perception of family by stating, “Families are now based more on voluntary ties, choices, and needs than on presumed obligation, particularly as people age” (p. 913). The general response to the challenge of defining the family unit has typically been to offer broad and flexible definitions. For example, Blieszner and Bedford (1997) claimed, “A family is a set of relationships determined by biology, adoption, marriage, and, in some societies, social designation, and existing even in the absence of contact or affective involvement, and, in some cases, even after the death of certain members” (p. 526). In contrast to this attempt to define family in light of all the determining factors, Garwick, Detzner, and Boss (1994) defined the family for the purpose of their research as essentially being what the family said it was. These researchers emphasized the personal nature and the individual’s conceptualization of family, and subsequently concluded, “The family composition was defined by the primary caregiver and his or her family, not by the researcher” (p. 328). The difficulty of conceptualizing family and the subsequent inconsistency of conceptual definitions presents an interesting challenge to the family researcher.
The Changing Understandings of Cognitive Impairment

Cognitive impairment (CI) is a broad term that refers to various diseases that affect one's ability to function at an appropriate cognitive level (CIHR Institute of Aging, 2008; Miller, 2004). Though CI is not a diagnosis in itself, there are two diagnoses that exist under the umbrella of CI: dementia and mild cognitive impairment (MCI) (CIHR Institute of Aging, 2008). Though more specific than CI, dementia is a term that encapsulates a number of different diseases. The most common and well known form of dementia is AD (Alzheimer Society of Canada, 2008). Other dementias include vascular dementia, frontotemporal dementia, Lewy body dementia, Creutzfeldt-Jakob disease (Alzheimer Society of Canada, 2008). The second category, MCI, is a more recent diagnosis that captures those individuals that are experiencing CI but who do not meet the criteria for a diagnosis of dementia (Advisory Committee, 2007). Though dementia and MCI are distinct diagnoses, and CI is the overarching term, these terms are often misused or used interchangeably in common talk (Miller, 2004). Further, as these diagnoses share many similar features, the knowledge derived from studying one category or subcategory is commonly drawn upon to inform other categories. A vast majority of the literature pertaining to CI is captured in the dementia literature. Therefore a review of the CI literature includes primarily literature that addresses dementia, and specifically AD.

Within the biomedical model, dementia is frequently described as a progressive, degenerative disease that results in cognitive impairment and an increased dependency on others to provide care (Alzheimer Society of Canada, 2005b; Chertkow, 2008; Woods et al., 2003). A diagnosis of AD is typically made based on the criteria that a person experiences memory impairment and at least one more cognitive deficit such as aphasia,
apraxia, agnosia, or disturbance in executive functioning (Advisory Committee, 2007; Kelley & Petersen, 2007). A diagnosis of MCI is typically made when an individual experiences cognitive impairment that cannot be accounted for by other ailments and the criteria for diagnosing dementia are not met, usually because there is not a second sphere of cognitive impairment or because the deficits are not significantly affecting the individual’s daily living (Advisory Committee, 2007). Though distinct diagnoses, there is a high likelihood that MCI will progress to AD, with a rate of 16 percent per year (Advisory Committee, 2007)

Family Caregiving for Persons with Cognitive Impairment

Though family caregiving occurs in the context of many different illnesses and injuries throughout the lifespan, the majority of research addressing the provision of care by the family to older adults is in light of a diagnosis related to cognitive impairment, commonly dementia. There are many reasons for the emphasis on dementia in the family caregiving literature. First, there is a high prevalence of dementia in the older adult population (Alzheimer Society of Canada, 2005a) and the population is aging (Miller, 2004). Second, health care restructuring as well as personal and familial preferences have resulted in approximately half of the growing number of persons with dementia residing at home with almost all of these persons receiving assistance from their families (Alzheimer Society of Canada, 2005a). Third, earlier diagnosis has led to an increased amount of time a person lives with a diagnosis of dementia, with an average duration of eight to twelve years (Alzheimer Society of Canada, 2005b). Finally, the nature of the disease renders the experience of caring for a relative with dementia to be particularly
complex. In light of these facts and the identified complexity of the experience, the importance of understanding the family caregiving experience as it pertains to dementia is evident.

**Caregiver Burden**

Early family caregiving research largely focused on the concept of caregiver burden (e.g. Montgomery, Gonyea & Hooyman, 1985, Zarit, 1980). Broadly speaking, caregiver burden is the emotional, physical, and financial toll of providing care (George & Gwyther, 1986). The conceptualization of caregiver burden however has evolved considerably in the three decades that it has been discussed and quantified in the gerontological literature (e.g., Montgomery et al., 1985; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Pearl, Mullan, Semple & Skaff, 1990; Vitaliano, Young, & Russo, 1991; Zarit, 1980). Much of the evolution of the concept of caregiver burden and the corresponding measurement tools has been the result of an increased understanding of what factors contribute, or may contribute, to caregiver burden. In a quest to understand which variables affect caregiver burden, a wide range of issues have been studied as they relate to measures of caregiver burden. Examples of variables examined include the physical health of the caregiver (Pratt, Wright, & Schmall, 1987), the frequency of ‘problem behaviours’ (Matsumoto et al., 2007), and the care recipient’s abilities to perform activities of daily living (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). The resulting literature offers a bleak picture of the caregiving experience in which the experience differs only by the amount of burden one experiences, implying that
burden is not only inevitable but also the predominant sense derived from the caregiving experience.

Though the caregiver burden research has contributed some valuable information to the family caregiver literature, the emphasis on caregiver burden has received a significant amount of criticism. Not only does this focus on burden provide a bleak view of the experience, Clarke (1998) claims that this focus in the research, with an abundance of negativity, has created additional stress for family caregivers. Family members seeking information or guidance on their role as caregiver are inundated with information on what factors are likely to contribute to the difficulty of their experience and little in the way of encouragement or empathy. Increasingly, the general consensus among researchers and practitioners is that understanding the caregiver experience through the concept of caregiver burden fails to provide a comprehensive view of the experience.

*Family Research Beyond Burden*

In order to better understand the family caregiving experience, there has been an increasing plea in the research literature to acknowledge and learn about the relational aspect of caregiving (Keady & Nolan, 2003; Perry, 2004; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007). This growing body of literature addresses issues pertaining to the relationship between caregiver and care recipient and the broader experience of giving and receiving care. From this literature emerged the acknowledgement that family caregiving is far more than the mundane completion of caregiving tasks.

Various researchers have examined the caregiving experience as it pertains to a specific type of relation (e.g. Baxter, Braithwaite, Golish, & Lehti, 2001; Kirsi,
Hervonen, & Jylha, 2000; Russel, 2001). The spousal relation has been the focus of the majority of this research. Preserving the identity of the person who has dementia is an important theme in the spousal caregiving literature (Davies, 2007; Jansson, Nordberg & Grafstrom, 2001). Perry and O'Connor (2002) found that spouses’ experience of caregiving was guided by the principle of preserving the personhood of their loved one. They identified four strategies: maintaining continuity, sustaining existing competencies, protecting the partner from incompetence, and strategizing public encounters. Knowing the person before the onset of disease provided the spouses with the opportunity to distinguish the person from the disease.

In addition to the spousal relation, understanding the experience of daughters caring for a parent, most commonly a mother, has increasingly received attention as the prevalence of this relationship rises (Armstrong & Armstrong, 2004). This relationship is frequently discussed in terms of its dynamic nature (Forbat, 2003; Goldsteen, Abma, Oeseburg, Verkerk, Verhey, & Widdershoven, 2007). For example, Perry (2004) described the daughters’ journey of caregiving as a process of “mastering the 3 R’s of (re)calling, (re)learning, and (re)adjusting”. She used the “(re)” to emphasize the daughters’ deconstruction of their relationships with their mothers and then rebuilding it with new understandings. Ward-Griffin and colleagues (2007) describe four dynamic types of relationships between mothers and caregiving daughters that varied as to whether they were task- or emotion-focused and whether they were based on strengths or deficits.

The literature examining specific relations between family caregiver and care recipient describes how these experiences draw on knowing the person prior to the onset of dementia and reconstructing the relationship as the dementia progresses. It is not
surprising therefore that the nature and quality of the relationship prior to illness plays a significant role in the caregiving experience (Fisher & Lieberman, 1994; Globerman, 1994; MacRae, 2002; Snyder, 2002; Steadman, Tremont, & Davis, 2007; Ward-Griffin et al., 2007). Forbat’s (2003) discursive analysis of the accounts of a mother with dementia and her caregiving daughter provide a clear illustration of the significance of the relationship prior to illness. The author summarizes the caregiving relationship by stating, “Longstanding tensions which, although not caused by dementia, do seem to be exacerbated by it. The relational difficulties evident…can be seen as a function of malignancy that has a historical basis in their earlier relationship” (p. 73). Though the relationship between caregiver and care recipient is altered with the presence of dementia, the impact of the prior relationship cannot be underestimated.

Unit of Analysis in Family Caregiving Research

In the overly simplified context of one individual receiving care from another individual it is reasonable to examine this relationship in isolation. However, most ‘family’ caregiving relationships take place within the context of a family. Garwick and colleagues (1994) provide the reminder, “Caregiving for the Alzheimer patient typically takes place within the context of a family whose members’ share a history of meanings developed over a lifetime” (p. 330). This family context, including the many relationships that exist within a family unit, has been largely absent in the literature.

Despite a large body of literature that claims to be ‘family research’, the majority of this research is conducted through the words of only one family member (Astedt-Kurki et al., 2001). This overwhelming focus on one family member in studies that claim to
study the 'family caregiving' experience has previously and continues to prompt the question, "Who is the family in family caregiving?" In their review of the family caregiving literature, with few exceptions, the family referred to in the family caregiving research consisted of one individual family member (Keating, Kerr, Warren, Grace, & Wertenberger, 1994). These researchers articulate the irony of the abundant family caregiving research, stating, "This research has shed little light on the question of whether families provide care or on who comprises the caregiving family" (p. 270).

Though there is value in the perspective of one individual family member, this perspective represents neither the perspectives of other family members nor the family as a unit. Though there are only a small number of studies that include multiple members of the same family, these studies have effectively demonstrated that one family member's account of the situation and experience is not representative of that of other family members (Garwick et al., 1994; Globerman, 1994; Perry & Olshansky, 1996). By interviewing multiple family members, insight is gained into the interactions that occur within families to create meaning, share responsibilities, resolve or create conflict, and all the many intricacies of the family caregiving experience (Forbat, 2003; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003). Brody (1990) states, "Looking at different family members separately with tunnel vision focus does not illuminate the complex manner in which various sets of relationships are layered and intricately interwoven" (p. 31). The complexity of the family unit was illustrated in Purves’ (2006) research that focused primarily on family conversation. In Purves’ study, multiple family members were interviewed and conversations between family members were analyzed. Effectively demonstrated in her research was the value of obtaining multiple perspectives within one
family and the notion that the various relationships within a family influence the other family relationships. Globerman (1994; 1995) also captured the voice of multiple family members in families affected by AD. In this research, she discussed how family members assumed various roles in the context of caregiving that were reflective of the roles each family member assumed in the history of the family.

While the historical roles in the family influence the establishment of the caregiving family, the scope of the roles are often challenged with the introduction of an illness. Pecchioni, Thompson, and Anderson (2006) state, “Having a seriously ill family member alters the ways in which family members interact with each other and the responsibilities each person takes on in the family system” (p. 458). Often there is uncertainty associated with the expectations of the altered roles within the caregiving family. Referred to as ‘role ambiguity’, the process of adapting to changing roles frequently led to communication problems and conflicts (Blieszner, Roberto, Wilcox, Barham & Winston, 2007). The history of the family, the relationships, and the process of responding to caregiving needs influences the experience of family caregiving in a way that is not adequately captured in the current caregiving literature.

Insight from the Person who has Cognitive Impairment

Though the literature pertaining to persons who have dementia is vast, there is ironically little research that actually focuses on the experience of having a diagnosis of dementia. More than a decade ago Cotrell and Schulz (1993) criticized the state of the literature, stating, “In the majority of research on AD, the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our
understanding of the illness and its course” (p. 205). Though this research is often logistically and ethically challenging (Vass, Minardi, Ward, Aggarwal, Garfield, & Cybyk, 2003), it is a necessary viewpoint to better understand the disease. There is a small but growing body of literature that presents the unique and valuable perspective offered by those living with a diagnosis of dementia. The literature that is available provides insight into how the person who has dementia copes with a diagnosis (Clare, 2002; Clare, 2003), experiences the symptoms (Phinney & Chesla, 2003), engages in meaningful communication (Acton, Mayhew, Hopkins, & Yauk, 1999) and receives the care that is offered (Ward-Griffin, Bol, & Oudshoorn, 2006). Much of the literature that represents the perspective of the person who has dementia highlights the significance of communication in the dementia experience (Acton et al., 1999; Clare, 2003; Phinney, 1998; Phinney & Chesla, 2003; Purves, 2006).

Communication in Families with Cognitive Impairment

In examining communication in the context of dementia, it is important to acknowledge that this illness is unique in that communication impairment is inherent in the disease process. Communication in the context of dementia therefore is unlike communication in the context of, for example, cancer where communication can be studied in the context of the illness but without the illness having a direct impact on communication abilities. For this reason, many of the theories that pertain to family and communication in the context of illness do not fit for the illness of dementia.
Communication Abilities and Cognitive Impairment

All persons with dementia experience communication problems to some degree (Byrne & Orange, 2005; Orange & Colton-Hudson, 1998). Often noted as one of the first presenting symptoms of dementia, changes in communication abilities continue throughout the progression of the disease (Byrne & Orange, 2005; Snyder, 2002). Early in the disease process, a person often experiences word retrieval difficulties or the use of empty or substitute words (Byrne & Orange, 2005; Kempler, 1995). This worsens in the moderate stage of the disease in addition to overuse of pronouns and poor topic maintenance, often rendering the conversation difficult to follow (Kempler, 1995). Extra time is required to process information and retrieve words. In some cases of advanced dementia, persons are completely aphasic (Kemper & Hummert, 1997).

Recently, the significance of these changes in communication has been studied from the perspective of the person who has AD. In Phinney’s (1998) phenomenological study that explored the experience of living with the symptoms of AD, three of the five themes that emerged were related to aspects of communication. The participants referred to being unable to remember, with reference to topics of conversation or factual information, difficulty expressing oneself, and difficulty participating in conversations. In another study, individuals with AD described conversations as being slow and halting as they had to pause and consider how to best express themselves (Phinney & Chelsa, 2003).

While the person who has dementia experiences changes in communication abilities, Kitwood (1997) convincingly argued that not all of the impairments experienced by a person with dementia could be explained by neuropathology. He claimed that the
attitude of the person communicating with the person with AD has a significant influence on a person's communication abilities and experience. The attitude of the communication partner, including whether it is perceived that the person with dementia has the ability to communicate worthy information, can either promote the abilities of the person with dementia or exacerbate their communication impairments.

**Communicating with a Person who has Cognitive Impairment**

While the communication partner significantly influences the ability of the person who has dementia to communicate effectively, problems related to communication are frequently cited as the greatest source of stress for those in the caregiver role (Muo, Schindler, Vernero, Schindler, Ferrario, & Frisoni, 2005; Small, Geldart, & Gutman, 2000). Communication is increasingly being acknowledged as a factor that influences other realms of the caregiving experience. For example, Savundranayagam, Hummer, and Montgomery (2005) showed that communication is a mediating link between measures of burden and factors such as the progression of disease and the frequency of problem behaviors. While communication affects measures of caregiver burden directly and as a mediating factor, the broader communication experience of the caregiving family highlights a large gap in the understanding of communication and the family caregiving experience.

Though a number of strategies to enhance and improve communication are suggested in the literature, few studies have been conducted to evaluate their effectiveness (Acton, Yauk, Hopkins, & Mayhew, 2007; Small, Gutman, Makela, & Hillhouse, 2003). Small and colleagues (2003) studied the use and the effectiveness of
ten common communication strategies recommended to family caregivers by health care providers. They found that the frequency with which the strategies were used varied and that some, such as speaking slowly, did not contribute significantly to effective communication. In a study by Small and Perry (2005), the use of yes-no, rather than open ended, questions resulted in more successful communication. However, the researchers noted that the success of open-ended questions depended on what memory was required to answer the question, with more success arising when semantic memory, rather than episodic memory was required. Muller and Guendouzi (2005) concluded in their research that strategies to promote effective communication must be equally dynamic as the nature of communication with persons with dementia.

Research Questions

Changes in communication are inevitable in the context of dementia. These changes are commonly acknowledged as a source of stress and frustration for family caregivers and persons with dementia. In light of the importance of communication and the role of the family, it is essential to establish an understanding of how family members perceive communication with their relative who has dementia, the contextual elements that contribute to this perception, and how these individual perceptions influence the family as a unit. The aim of this study is to increase the understanding of a family’s experience of communicating with a relative who has CI.
The following questions guided this study:

1. How did individual family members perceive and describe communication with their relative with CI? What meaning was given to the interactions with their relative with CI, and how was this meaning arrived at?

2. What were the similarities and differences between individual family members’ experiences and perceptions of communicating with their relative with CI?

3. What patterns of communication between family members characterized the family’s communication experience? What components of the family context (e.g. values, expectations) were perceived to influence the experience of the family?

While all three questions guided this study, the focus of this study became the third question that addressed the communication experience of the family as a unit. While the interview questions asked about the broad experience of communication, the experience as it related to the family context became the central focus emerged from the interviews and the analysis. The findings of the first two research questions, addressing the communication experience of the individual family members, will be discussed as they relate to the family experience.
CHAPTER 3

METHODOLOGY

The Case Study

This study is a qualitative single case study exploring the meaning and the experience of communicating with a relative with dementia for a family. Case study research is "the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (Stake, 1995, p. xi). The case study approach is particularly useful when there is not a clear distinction between the phenomenon and the context, and the context is assumed to be relevant. Most of the knowledge of families and dementia presented in the literature consists of pieces of the experience that have been fragmented from the context within which exists the experience of CI. The case study approach, with the focus on a single case and acknowledgment of context, encourages the understanding of the pieces of the family’s experience as they exist together.

Researchers have used a qualitative case study approach when it is believed that the phenomenon of interest is significantly influenced by the family context (e.g., Backett-Milburn & Harden, 2004; McAndrew & Warne, 2005). Backett-Milburn and Harden (2004) emphasized in their case study of families’ negotiation of risk that the case study approach was invaluable in allowing for exploration of the complexity of the family unit as the context within which family members live their lives, acknowledging the family as the arena where beliefs are shaped and constantly renegotiated. The case study method is also used when the phenomenon of interest or experience is considered
to be dynamic and multidimensional (Docherty, Sandelowski, & Preisser, 2006). As the family and illness context cannot be isolated from the experience of communicating with a relative who has CI, the case study approach appropriately allows for the in-depth analysis of contextual elements that influence the experience of communication.

A frequent criticism of case study research is the inability to generalize the findings to a larger population. Stake (1995) argues that the “real business of a case study is particularization, not generalization” (p. 8). Sandelowski (1996) also addresses this criticism by emphasizing that these studies are not conducted with the intention of making broad generalizations. Though the ability to generalize is valuable in research, Sandelowski criticizes the emphasis placed on broad generalizability in qualitative research. Rather, it is argued that having knowledge of the particulars is a necessary and important component of generating knowledge and theory (Stake, 1995; Sandelowski, 1996). Sandelowski asserts that when theorization of an experience is premature, the study of a case “acts as a heuristic device for generating knowledge” (p.526). Knowledge of what happens for a particular family can provide researchers and clinicians with insight into new and productive ways to formulate questions and to develop hypotheses and theories (Sandelowski, 1996).

Symbolic Interactionism

In studying the family unit, Sabourin (2006) discusses the value of applying the theory of Symbolic Interactionism as it “allows us to focus on the complexities of mundane reality” (p.46). The theory of Symbolic Interactionism was selected to inform
and direct this study. Blumer (1969) addressed three premises of Symbolic Interactionism:

The first premise is that human beings act toward things on the basis of the meaning that the things have for them... The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (p. 2)

The incorporation of Symbolic Interactionism into the study of a family is appropriate as it emphasizes the interpretation and meaning derived from an individuals' interaction with others. Acknowledging that the family is an important social group, Symbolic Interactionism becomes especially valuable because of “its assertion that individuals develop both a concept of self and their individual identities through social interaction, enabling them to independently assess and assign value to their family activities” (LaRossa & Reitzes, 1993, p. 136). Garwick and colleagues (1994) comment that “Symbolic Interactionism is particularly appropriate for families that are caring for a person with Alzheimer's disease since the disease affects family interaction and communication.” (p. 330).

Procedures

Recruitment

After gaining approval from the Behavioural Research Ethics Board of the affiliated university, multiple recruitment strategies were used to locate a family willing and able to participate. A letter of information about the study (see Appendix A) was sent by mail to primary caregivers of persons with AD who were previously involved in a
related study about AD and who had agreed to receive additional study announcements. A flyer explaining the study was also available for distribution through colleagues to potential participants (see Appendix A). Recipients of the letter or the flyer who were interested in participating were instructed to contact the researcher by telephone or complete the enclosed form and mail it to the researcher in the self-addressed, stamped envelope provided. The researcher then telephoned the interested family member to respond to any questions and to further discuss the inclusion criteria to ensure that the criteria were met. The inclusion criteria included the following:

1. The family includes one person diagnosed with Alzheimer disease or related dementia.
2. The diagnosed person lives in the community (i.e., not in a long-term care facility).
3. All participants are fluent English speakers and English is the language spoken within the family.
4. At least three members of the family are willing to participate in the study.

The challenge of defining family was previously discussed. In this study, "family" was not defined by the researcher to allow for the participating family to conceptualize who is included in the family for the person with dementia. Though vague, this definition recognizes and allows for the diversity within family units that is encountered in community and clinical settings (Garwick et al., 1994). It was not required that the person with CI participate in the study. This was largely due to the research questions pertaining to the experience of the family members in communicating with their relative with CI. Also, the researchers' previous research experience revealed that many families exclude
themselves from participating in research if there is a risk that their family member with CI will be exposed to a negative experience.

Sample

The participating family in this study is represented in the genogram (Figure 1). Members of the family who participated in the study are depicted with an asterix beside their assigned pseudonyms.

Figure 1. Genogram of the participating family.

Louise is an 89 year old mother of five children. She has a diagnosis of “cognitive impairment” that was made by her long-term family physician two years prior to the study. At the time of this diagnosis, Louise scored 26 out of 30 on the Mini-Mental Status Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). Louise’s diagnosis is referred to by her family as CI, the same term used by her family physician. As previously mentioned, CI is the broad term that encapsulates all types of dementia and MCI. While not an official diagnosis, the term CI will be used when referring to Louise’s condition in keeping with the family’s reference to CI as the diagnosis. While Louise’s official diagnosis two years prior to the study may have been MCI, at the time of the study she
was experiencing many symptoms, including memory loss and impaired judgment, and her CI clearly affected her daily life. Though the family continues to refer to CI, Louise's impairments seem to align with dementia.

Included in Louise's family is Anna, the eldest of the children. She has regular phone contact with Louise but does not live in the same city. Betty, the second eldest, re-established connection with Louise prior to the study after about 25 years of being estranged from the family. Sarah, the middle child, has regular contact with Louise and, though she does not live in the same city, she often stays with Louise. Jack, the only son, does not live in the same city as Louise and has very little contact with her, though he is in contact with Kate. Kate, the youngest child, is identified by herself and her siblings as the primary caregiver for Louise. Kate was the family member that contacted the researcher and subsequently was asked to invite other family members to participate in the study. It is unclear what family members Kate actually invited to participate in the study. It is possible that Kate chose only to invite the family members who did end up participating in the study, or she may have invited some family members who chose to decline. Kate lives in the same house as Louise, in a separate upstairs suite with her husband Dave. Dave and Kate have been married for 17 years. By extending the invitation to participate in the study through Kate, the family members that participated were Kate, Sarah, and Dave. After the researcher met the participants, all participants felt that Louise would like to be involved. Subsequently, the researcher submitted an amendment to the ethics board for approval to interview Louise. This amendment was accepted and Louise subsequently participated in the study.
Data Collection

The primary means of collecting data for this study was through the interview process, a widely used means of collecting data in qualitative research. Though this method relies on the participant’s willingness and ability to articulate their experiences, thoughts, and feelings, interviewing often provides rich information about the phenomenon in question. Participants, prompted by open-ended questions, were given the opportunity to tell their own stories in their own words. As a case study requires a large amount of rich data from a variety of sources (Stake, 1995), each participant, with the exception of Louise, met with the researcher three times for the purpose of data collection. These meetings consisted of two individual interviews and an interview with all participating family members. The data collection procedure differed for the person with a diagnosis of cognitive impairment, Louise. Louise was interviewed once and did not participate in the family interview.

First Individual Interview

Though the family was the unit of focus, it is the individuals within the family that comprise the family. Each participating family member was interviewed separately. This was done to provide the family member with an opportunity to discuss the experience in privacy, with less threat of hurting, offending or being challenged by other family members. In Thomas’ (1987) study of families with children who were ventilated, interviews with individual family members revealed family secrets, individual assessments of other members’ capacities, strengths, and weaknesses, as well as personal
fears and fatigue. This information was omitted or modified by family members during
the interview with the entire family, indicating a sense of restriction as to what
individuals felt they would or could share with other members (Thomas, 1987).

In order to gain an in-depth understanding of the individual family members’
perspectives, without the possible censorship that may arise during a group interview,
each of the participating family members were interviewed independently. The first
individual interview was intended to collect data pertaining to the individual family
members’ experience of communicating with their relative who has CI. These interviews
were conducted at a time and a location convenient to the participant. This semi-
structured interview was approximately one hour in duration and was audio recorded to
facilitate further analysis of the interview content. The family member was asked open-
ended, general and specific questions about their communication experience with the
relative who has CI (see Appendix B).

For the interview with the family member who has CI, a similar format was used,
though the interview was less structured than the other individual interviews (see
Appendix B). The focus of the interview was her perception of her family and the
interactions that she has with each of her family members. The terms CI and AD were
used in discussing the consent; however Louise did not refer to having a diagnosis related
to CI. In response to specific prompts about symptoms of CI, such as memory loss, she
did briefly allude to the significance, or rather the insignificance of these symptoms.
Family Interview

Astedt-Kurki and Hopia (1996) define the family interview as “a method of data collection where all participating members of the family unit are involved in a group setting specifically designed for the purpose of gathering information” (p.507). These researchers use this definition to distinguish the family interview for research from the family interview for clinical purposes. This means of data collection offers the opportunity for data to be collected through in-depth dialogue between family members rather than between researcher and family (Astedt-Kurki & Hopia, 1996). The family interview allows the family to respond to each other’s comments, provides insight into shared meanings, and gives the researcher a sense of the family dynamics and interactions (Wright & Leahey, 2005). Data derived from the family interview often provides information on the characteristics, attitudes, and events of the family as observed by family members (Astedt-Kurki et al., 2001).

The family interview occurred at a time convenient to the family in the home that is shared by Kate, Dave and Louise. This interview was scheduled after the completion of all the initial individual interviews but prior to the second interviews and the interview with the mother. Discussion of the issues identified as important by the individual family members were promoted in order to obtain a family perspective. Though the family was asked questions similar to those asked in the individual interviews (see Appendix B), the emphasis was on the family’s approach to communicating with the relative with CI and the process of negotiating this approach. The family interview was also audio taped. As previously mentioned, Louise did not participate in the family interview. This decision
was made based on the researcher and the other participants' concern that information would be censored in an attempt to avoid embarrassing or upsetting their mother.

Second Individual Interview

The second individual interview offered an opportunity for participants to elaborate on or clarify any information previously offered. The researcher also asked questions to clarify information previously shared by the participants in the individual or family interview. Furthermore, as time had elapsed between the interviews, the researcher also requested an update on the situation, such as whether any changes had been noted since the previous interviews. Similar to the other interviews, these interviews were audio recorded.

Data Analysis

Transcription

To facilitate analysis of the data, all audio recorded interviews were transcribed verbatim by the researcher. Transcription occurred shortly after each interview to allow for analysis to begin while still in the process of collecting data. The researcher, appreciating the complexity of accurate transcription and the multitude of components that need to be considered (MacLean, Meyer, & Estable, 2004), followed a clear guideline regarding the transcription format. Included in the transcription were conversation fillers and utterances, such as uh-hm. Emotional content, such as laughing and crying, was also transcribed (e.g., (laughing)). Where words were not clear, "(____??)" was written within the transcript. Identifying information, such as names and
places, were omitted or assigned a pseudonym to promote confidentiality. Each family member was assigned a pseudonym that was used to identify the person in all data, including references made by other family members about that person. The family interview was transcribed in the same way, with the identifiers being used prior to each person’s comments. The researcher checked the accuracy of each transcript against the corresponding audio recording and any errors were corrected.

Constant Comparative Analysis

In this qualitative case study, data was analyzed using a method of constant comparative analysis. This approach to analysis, commonly associated with grounded theory methodology and originally described by Glaser and Strauss (1967), is fitting for a number of reasons. First, this method of analysis evolved from the theory of Symbolic Interactionism (Holloway & Todres, 2006; Thorne, 2000), the theory informing this study. Furthermore, constant comparative analysis is particularly suited to “develop conceptualizations of the possible relations between various pieces of data” (Thorne, 2000, p.69). This approach to analysis provides a method of comparing the data and the relationships between various pieces of data at various levels of interest, or units of analysis.

A number of researchers and methodologists have described the process of constant comparative analysis, each offering slight variations in both the corresponding terminology and the analytic process (e.g., Dye, Schatz, Rosenberg, & Coleman, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The description of constant comparative analysis provided by Hutchinson and Wilson (2001) contains three levels of
codes: substantive codes, categories, and theoretical codes. Analysis of the data for this study was performed in congruence with Hutchinson and Wilson's (2001) account of this constant comparative analysis.

One of the key features of the constant comparative method is that data analysis and data collection occur simultaneously. Analysis of the first interview therefore began immediately following its transcription. The transcribed text was read to gain a sense of the interview in its entirety. Line-by-line in-vivo coding was then performed in which key phrases in the participant's own words are assigned to passages in the text. The in-vivo codes, or substantive codes, that were derived from the text were then examined to determine which substantive codes share meanings or incidents. These substantive codes were then grouped into categories, the second level of coding. The transition from substantive codes to categories involves an analytic process of questioning the relationships in the data, identifying the similarities and the differences between and among the codes. During this process, concept maps and memoing occurred in which thoughts about the in-vivo codes and the categories, including the rationale for the formation of the categories and the identified relationships, were recorded. Once all the first set of individual interviews were completed, the third level of coding began. The categories were examined to identify relationships among them, and categories were regrouped into more abstract theoretical codes. These theoretical codes or themes form the basis of the discussion regarding the experience of communicating with a relative with CI.

Theoretical coding occurred with consideration of the unit of analysis. The research questions for this study addressed the experience of both the individual family
members and the family as a whole. In conjunction with the research questions, the analysis of the data proceeded with consideration of the following three units of analysis: within the individual family member, between individual family members, and the family as a whole. Subsequently, the theoretical codes differed depending on the unit of analysis.

Rigor

"Without rigor, research is worthless, becomes fiction, and loses its utility" (Morse, Barrett, Mayan, Olson & Spiers, 2002, p. 2). To promote rigor in this study, an audit trail was kept throughout the research, recording details and rationales for decisions made pertaining to the data collection and analysis, especially the process of coding. This included keeping records of discussions the researcher had with the thesis committee about the study. Furthermore, rigor was promoted by recording thoughts, feelings, and potential sources of bias and how these potential biases were dealt with, ensuring the traceability of these issues. This process has also been identified as a valuable component of self-reflection. It was intended that the final analysis met the criteria of rigor.

Ethical Considerations

A number of ethical considerations were addressed in this research project. Challenges arose with respect to free and informed consent. In order for a participant to provide free and informed consent, the participant requires information about what participation will entail. Details about the data collection process, including the general topics addressed in the interviews, were provided in advance, though the exploratory nature of the study limited the amount of information that could be provided to
participants. This was a particularly significant challenge in obtaining consent from the participant with CI. The researcher’s concerns regarding the participant with CI’s ability to understand the nature of the study and participation was discussed with the primary caregiver. The primary caregiver in turn spoke with the participant with CI about the study and her voluntary involvement in the study for a couple of days prior to meeting with the researcher. A consent form (see Appendix C) was signed by each participant prior to participation in the study, including the participant with CI. Obtaining consent was an ongoing process throughout the duration of the project. Participants were encouraged to ask questions, seek clarification, and verbalize concerns at any time. Each participant was told that he or she had the right to refuse to respond, cease to participate in the project, or withdraw some or all of the data he or she provided at any time prior to the completion of the study.

Careful consideration of issues pertaining to privacy and confidentiality were necessary due to the small sample size and the fact that participants are members of the same family. Geographic references, ages, professions, and any other information that may identify the individuals in the study were omitted or altered. As the intention of the study was to speak of the experience of the family unit, difficulties arose in ensuring that the family was not identifiable. Discussions with the family regarding the issue of anonymity occurred prior to data collection, throughout the study, and prior to completion of the study. Emphasis was placed on the inability to guarantee that the family will remain anonymous to people who know the family as a unit. To mediate this issue, ongoing dialogue with the participants occurred to ensure that the final product of the study provided a level of anonymity that is satisfactory to each participant. Within the
family, there is the likelihood that the identity of an individual or the information
provided by an individual would be recognized by other family members. The researcher
sought approval from the corresponding participant for each direct quotation presented.
Though the depth of the information gathered in this study had the potential to be
compromised by the participants' ability to refuse to respond or withdraw information,
upholding the ethical principles pertaining to research conduct was essential.
CHAPTER 4
FINDINGS

Figure 2. Model of the findings

The findings that emerged from this study are represented in Figure 2. As previously mentioned, the data supported a focus on the third research question that addressed the communication experience of the family as a unit. This model illustrates a summary of the family’s interactions with their relative with CI and the way in which participating family members conceptualized the family. While the family as a whole was frequently referred to, it is important to distinguish between the broader concept of family, which includes those that are later referred to as on the outskirts, and the caregiving family, referred to as the core and consisting of the family members that participated in the study. There were three goals identified as driving many of the core family’s interactions with Louise: include, protect, and bring happiness. There were also three primary strategies used in the interactions with Louise: interpreting, scripting, and
translating. These strategies were often utilized to achieve the three goals. Briefly referred to, the family was conceptualized as having a core and outskirts. The three family members that made up the core of the family had three distinct caregiving roles: the Expert, the Trusted Visitor, and the Silent Supporter. In the following presentation of the emergent findings, each component of this model will be discussed in more detail. Furthermore, though the strategies and intentions were primarily discussed as they relate to the way in which participating family members communicated with Louise, there was also evidence that Louise engaged in these strategies with the same underlying intentions.

Goals

The data suggest that there were predominant goals that guided communication with Louise. When participating family members described their interactions, it was evident that communication did not occur haphazardly. When family members interacted with Louise it was with three specific goals in mind: include, protect, and bring happiness. Though various strategies were utilized in order to achieve these goals, which will be discussed later, the guiding incentive in their interactions was to achieve at least one of these three goals during conversation. Though each goal is presented independent of one another, in many situations the interactions occurred with the intention of achieving more than one goal concurrently.

Include

Family members described interacting with Louise in a way that was intended to make her feel that she was included. Keeping Louise included in a conversation often
involved consciously altering the nature of the conversation. Kate explains, “I work very hard to keep her included, to make sure she doesn’t feel left out or stupid in the conversation. Make sure she has time to speak and time to form an opinion. And just slowing right down.”

The desire to keep Louise included became particularly relevant in a group social situation, such as a dinner party or a family gathering. This was considered to be a situation in which Louise was at high risk of being excluded. Once it was identified that Louise was feeling “lost” or excluded from a conversation, family members intentionally interacted with her in order to re-include her in the conversation. Sarah and Kate described a situation in which their interactions were intended to re-include Louise:

Sarah: Say at a dinner party, she can easily become kind of isolated if we’re all yaking and talking. You look over and mom will appear completely lost.
Kate: You have to bring her back, and you have to ramp down the conversation so it’s more focused at her. You get people to ask her direct questions and let her respond and then actually bring her back into the conversation.
Sarah: Via a topic that she can probably participate in.
Kate: And it’s probably gonna be something like the cruise ships that she sees go by, Rick Steeves, her favourite television shows, what Holly her cat is doing. It’s not geopolitics. It’s just whatever is right here.

The process of keeping Louise included, or re-including her if she has become excluded was perceived by Sarah as a responsibility that she shared with her family:

I think it’s our responsibility to bring the conversation down to a level that she can participate in and enjoy and feel good about. To the small talking kind of things... The topic changes so she can participate in them. Asking her about a dinner party when we were younger, recalling when my kids were little; she loves that and she’ll chat away.
Protect

The need to protect Louise from conflict or confrontation was often discussed as a governing factor in their interactions with Louise. Most of the discussion on protecting Louise centered around protecting her from being burdened, embarrassed, or fearful.

To protect Louise from feeling burdened, Kate and Sarah spoke of how they do not go to their mother with their troubles:

Sarah: I never tell mom negative things about my life. I just don’t. And I think that’s kind of a shame because it doesn’t bring us closer... But I just don’t do that with mom. I wouldn’t go to mom.
Kate: Yeah. Neither would I. We’re both the competent, self-sufficient types.
Sarah: I’d rant and rave to somebody else easily but not to mom. Protection, I think. I think I see it as protection. I don’t want to load her down.

Some family members were reported as telling Louise all their troubles, and Kate and Sarah worried that Louise was left with the burden.

There were also interactions that aimed to protect Louise from being burdened by the hardships she had experienced in her life. Sarah described re-directing the conversation if Louise began speaking about upsetting time:

I have to deflect her when she talks about sadness things because she tends to dwell on the negative. So I have to kind of get her off that and go back to happier times... Say she’ll get onto talking about the stepmom and how mean she was and then she dwells on that and she starts crying. And I might just say to her, ‘What was the name of your street?’ or ‘Did your dad take you for ice cream very much?’ and then bang, she’s forgotten about that. She doesn’t recognize that I’m doing that, she doesn’t make a comment. I just have to get her off that track.

Kate also referred to keeping Louise away from “needle in the groove stories” that caused Louise to feel angry about past events in her life. Guiding Louise
away from recalling hardships in her life in order to protect her from these painful memories was a common goal in their interactions.

Protecting Louise from embarrassment was an intention that the family spoke of as something they have always tried to do, but they felt that they now did more frequently. Sarah recalled, “I guess mom’s always said stupid things sometimes, but all of our life I think we’ve always cushioned it. We’ve always helped her around it. We’ve joked her around it.” Kate also spoke of working to protect Louise from the embarrassment that is often associated with her tendency to interject seemingly random comments into a conversation:

If mom makes a comment that’s inappropriate or it’s a non sequitur you have to work hard to sort of weave it into the conversation so she doesn’t feel like she’s made an inappropriate conversation. I think we both make an effort to take that comment and just, ‘Well, that’s an interesting take on it. Yeah, I guess you could see it that way.’ We do that to avoid any kind of embarrassment because mom’s sensitive to embarrassment. She can be easily embarrassed... I’ve done it all my life. Avoid embarrassment. Make sure her comments are somehow woven in so that they actually do make sense even if they don’t.

Louise was described as a very anxious person and there was a sense of needing to protect her from her “irrational fear”. Kate described Louise as having “always been a fearful, nervous person who believed that you can’t have anything good but that it’ll be taken away from you.” She explained that as Louise’s cognitive abilities have declined her anxieties have increased, “When she gets an obscure idea in her head there’s just no reasoning power that she has left that she can reason her way out of it.” Though Sarah alluded to Louise’s fear as a concern, Kate spoke extensively about the impact Louise’s fear has on their daily life and the various interactions she has with Louise to “stop her from winding up into a panic attack”. Kate described Louise as often panicking about her
whereabouts, concerned that she had been kidnapped. In order to protect Louise from this fear, Kate described giving pertinent information about her plan in a way that minimized the chance that she would misconstrue the information, “When I talk to her I talk directly to her. I make eye contact. I get her to tell me what I just said to her back and I also write it on the white board.” The white board was used as a reminder of the plan, particularly with respect to the time Kate would be home. Kate explained how the written messages on the white board were used as a tool to protect Louise from her anxiety:

> It’s night. I’m out. She begins to panic. The first thing she does is look at that board and it will tell her what’s happening. The board is right next to the clock. She looks from the board, it says ten o’clock. She looks to the clock. It says 8:30. I’m hoping that that connection is made.

**Bring happiness**

Many of the interactions with Louise were with the intention of bringing her happiness. It was perceived that Louise enjoyed talking about certain things. Consequently, many of their conversations were described as small talk about particular topics. Kate explained:

> She really enjoys just natural beauty. If we’re just out walking she will always comment on any of the foliage, any of the landscaping, any of the trees, and the clouds. She gets real enjoyment out of that and she understands that and it never ceases to delight her. So that’s a high priority conversation.

The small talk that was often perceived as enjoyable and satisfying to Louise was not necessarily enjoyable to the communication partner. Sarah referred to the small talk as being difficult and tiresome because the conversations “don’t go anywhere really and it’s always the same thing”. Despite the lack of enjoyment that Sarah derived from the conversation itself, she describes initiating small talk to make Louise happy:
I might say, ‘What time is Eva coming over?’ and then she’ll tell me all about Eva, even though she’s told me a hundred times before. I might just give her a lead-in question so that when we’re having tea there’s conversation happening because otherwise it’s just this silence. I probably instigate the small talk a lot to avoid that we don’t just sit there… If there’s a silence I probably want to fill it up. Her past, the flowers, there’s things that I know she could probably talk on for about ten minutes. And I think it’s happier for her… When I bring up these topics I know it’ll give her probably five minutes and then I think she feels quite good because we’re out having coffee and we’re talking. I think I steer her towards safe small talk so that I can survive and listen one more time to the birds. And that she feels good about our time together.

Sarah described consciously altering her way of interacting with Louise in order to bring her happiness. She recalled how she has “softened” towards her mother in order to make her happy:

I used to be very strong around mom, bossy and overbearing at times, and I now will do anything to just, I guess keep her happy. I’m really conscious of that. The right questions, the right answers. You know, watching what I say. I’m really enjoying this time with mom where I have, it’s not really pretending, but it’s just making her really comfortable and at ease and happy. I’m very conscious of that.

Kate agreed with Sarah’s claim that she is conscious of interacting in a way that brings happiness. Family members interacted in a manner that was intended to bring Louise happiness, and they seemed to derive satisfaction by witnessing Louise experience happiness rather than the conversation itself.

Strategies

Three strategies emerged from the data as being instrumental in achieving their goals in the interactions with Louise. The three strategies were interpreting, scripting, and translating. These strategies were considered not only valuable but necessary in order to
communicate with Louise in an effective and desirable manner. Each strategy was either used on its own or in conjunction with another strategy to achieve the desired goal of the interaction. A description of each strategy and examples of their use will be presented.

Interpreting

Interpreting is a strategy that was described as the ability to understand the meaning behind Louise’s verbal and non-verbal communication. In order to interpret, it was felt that a person first had to recognize that information was there to be gathered and interpreting was then the ability to decipher the correct meaning of this information.

Kate and Sarah spoke repeatedly of the significant amount of information that was available through Louise’s body language. They spoke of Louise as someone who is “very disconnected from her emotions” and “never talks about how she’s feeling”. They subsequently relied heavily on their ability to interpret her non-verbal communication. Kate describes “trying to always figure out what she’s thinking and doing when she can’t actually even communicate that to me herself”. This strategy was used primarily to identify when Louise was feeling excluded, confused, or fearful.

The ability to accurately interpret Louise’s non verbal communication varied among family members. In order to accurately interpret, there was the sense that acknowledgement and an understanding of Louise’s impairments was essential and that these were often associated with time spent with Louise. Kate credited her long-standing caregiving relationship for her ability to interpret, “I know her better than she knows herself. I can tell just by her body language what’s going on… I’ve always looked after her”. She spoke of her ability to interpret not only Louise’s body language but also her
vocal tones and even her activity level. Kate claimed, “I can tell by her level of busyness if she’s anxious about something or if she’s feeling energetic or she’s feeling tired or whatever.” She elaborated further, stating, “There’s a whole number of body language and vocal clues that I pick up on that I know a lot of the family don’t. They just hear what she’s saying.” Sarah was also able to utilize this strategy effectively. She commented on having improved in her ability to interpret Louise’s interactions by observing and learning from Kate. For example, Kate talked about knowing that when Louise is stressed or unable to process information she often laughs: “She just laughs. That’s her response when she just doesn’t know what to do. She just giggles. And that’s interpreted by the other person as something good and I know that’s a stress response.” Sarah later commented: “Kate clued me in to that; that the giggles and laughter were not laughter and giggles. They were usually high stress.” Sarah’s ability to interpret Louise’s behaviors was notice by Kate. Kate commented on Sarah’s ability stating, “She’s getting much better at hearing those little slight verbal clues that mom will give or slight physical clues that all is not as she says.”

Kate spoke of encouraging others to be aware of information that was being shared non-verbally. For example, she encouraged Dave to “not just hear what the question is but you’ve got to hear what the real concern is underneath the question”. Dave spoke of the challenge associated with interpreting Louise’s non-verbal communication. He referred to her as being “labile” and that her non-verbal communication was often quite complex. Dave stated:

She often appears to be very upset about something, on the verge of tears, and presumably she is upset to some extent but not to the extent it appears. My understanding is that she has this outward show that’s out of proportion with what she’s actually feeling or out of proportion with how
she should be feeling. So it’s better not to draw attention to that or to behave as if she’s actually feeling that upset about something. I actually have to kind of ignore her non-verbal communication in order to not make her uncomfortable.

Dave commented that he can often decipher when the outward show does not match with how she is actually feeling because it is a “sudden onset and sudden going away.”

Interpreting was frequently done to identify when Louise was feeling “lost” or “excluded” in a conversation. Kate referred to Louise pushing away from the table and initiating the cleanup process, regardless of whether a meal is finished, as an indicator that she felt more useful elsewhere. Sarah talked about being able to “see that she’s actually just sagging right in front of my eyes because she’s not part of the conversation anymore”. Being able to interpret Louise’s body language to know when she felt excluded was deemed necessary in order to keep her included.

*Scripting*

Scripting was described as a strategy that entailed preparing for and planning interactions with Louise, usually during one-on-one interactions. Frequently in these prepared interactions, information was intentionally omitted with the purpose of protecting Louise either by excluding upsetting information or to maximize the likelihood that she would understand the information that was conveyed. On other occasions, scripting was described as following a particular pattern of conversation with expected questions and answers in order to bring happiness. Use of this strategy highlighted the thought and effort that was invested in the interactions.
The process of scripting a portion of a conversation and a willingness to follow the expectations was described as a means of promoting social conversation. In such situations, a particular topic that Louise was interested in was introduced into a conversation. These were topics that Louise was capable of engaging in and enjoyed discussing. On other occasions, interactions were planned with the intention of reassuring Louise if she became anxious. Kate and Sarah discussed a period of time during which Louise would get increasingly panicked if she was unable to reach Sarah by telephone. They report realizing that her panic could be alleviated by assuring Louise that Sarah's whereabouts was known. It was established by "word of mouth" among everyone that when Louise phoned that they would say, 'Everything's fine. I just saw her.' Family and friends were "coached" never to say that they did not know of Sarah's whereabouts.

Scripting also occurred in order to optimize her ability to understand information that was being conveyed. This was described as a conscious process that was initiated by Louise's communication partner. Sarah referred to keeping her messages simple, "I'm conscious that I'm not saying as much as I would normally. I'm kind of editing what I'm going to say." Kate then commented, "You're not giving her as much detail. So it's a simplified sort of script." To which Sarah responded, "The simplest way possible." The scripting of information to be shared was used on a daily basis by Kate to inform Louise of the day's schedule. She spoke of informing Louise of her plan for the day, giving her the necessary information in the most reassuring and simplest way possible, and keeping her sentences to a maximum of seven words. To reinforce this message, simple notes were written in large letters on a large whiteboard in Louise's kitchen.
Conversations with Louise were sometimes described as following a particular pattern. These patterned conversations consisted of expected questions and responses.

Sarah and Kate discussed the pattern when Sarah comes to visit:

Sarah: When I arrive it’s the same pattern, the same questions. It’s usually always the same.
Kate: The standard social interaction number five. You kind of have to let her go through that order. If you interrupt that order sometimes it’s a little disconcerting.
Sarah: But it’s important to her. It’s very important that she’s polite. I don’t see it as totally enjoyable. I see it as just something that she knows is necessary, that you have to do.
Kate: And I don’t think she actually listens to any of the answers that she receives during that time.
Sarah: No. She doesn’t listen.
Researcher: But you still answer?
Sarah: Yes. As she’s changing I think about my answer and I plan it more. Giver her the answer she wants. Whereas a few years ago I might get in a snit or I might say, ‘You’ve already asked that.’ So very much fitting with the question.

Sarah clearly exhibited a reluctance to stray from the expected pattern of interaction with Louise despite the lack of enjoyment she felt from the interaction.

Translating

Translating was described as a strategy that involved repeating, rephrasing, or simplifying information. This strategy was primarily used in group settings to help Louise understand the content of a conversation. Louise was described as being “unable to follow a lot of fast conversation. She can’t follow multiple people at once”.

Subsequently, to include her in the conversation, it was believed that someone had to translate for her. Like with interpreting, the ability to translate in a manner that enabled Louise to understand varied among the family.
Kate described translating for Louise during a conversation with a number of people at the dinner table:

I would be beside her making sure she was understanding what was said. If I noticed her confused, I’d be repeating things directly to her. If everyone was laughing and she wasn’t getting the joke, I’d be translating. You know, repeating and explaining things to her... (She) needs things presented directly to her in a more simplified way.

Having someone continually break the conversation down to a level that she could understand was perceived as necessary to keep her engaged. When someone was not available to translate for Louise, they often observed her pushing away from the table, which they interpreted as an indicator that they had “completely lost her”.

In addition to translating so Louise could better understanding the conversation, translation was also used to prompt others to include Louise. For example, by observing the level at which Kate translated, others were made aware of or reminded of the simplicity required in order for Louise to follow a conversation. Kate explains, “I guess the level at which I’m talking to her will cue the person who’s the centre of the conversation to address her more on her level.”

Family members also translated Louise’s comments, often weaving inappropriate comments from Louise into the conversation in order to keep her from being embarrassed. In reporting the goal of protecting Louise from embarrassment Kate talked about merging her random comments into the conversation. This ability to take an inappropriate comment and make it fit with the conversation was also an example of the strategy of translation.

Though these three goals and three strategies have been discussed as they pertain to family members’ interactions with Louise, it is important to note that Louise also
demonstrated a desire to achieve the same goals, sometimes using the same strategies in her interactions with others. Although Louise was described as having little insight into her interactions and being “a visceral responder”, she did demonstrate the ability to achieve particular goals in her interactions.

Louise spoke of her need and desire to interact in a way that was inclusive. With her children, Louise referred to Betty being included in her will. Louise stated, “She’s in my will evenly, as the others are. Nothing harsh or anything.” She also alluded to her desire to protect others from being burdened. Louise commented that she tries to not ask Kate and Dave for too much, “I don’t overdo it. I mean, I do as much as I possibly can... I try not to ask too much because they’ve got their life.” Louise also worried about Kate going out after dark by herself because of the risk of being kidnapped. Although all the participating family members perceived these fears as irrational, the fears were nonetheless a reflection of her desire to protect Kate from harm. Louise’s desire to bring happiness to others through her interactions was evidenced by her ability to listen to those that are in need and offer “advice that is actually really pertinent”. Sarah commented that a friend who visited Louise gratefully reported that Louise had “listened and she understood and she gave good advice”.

Louise was also described as someone who could use the same strategies that often get used by others in their interactions with her. Louise’s ability to interpret what others want was frequently referred to something she did subconsciously. Kate explained, “She’s very much a pleaser. If there’s an expectation of a certain answer, it’s not conscious but... she’ll pick up from them what they really want and she’ll give it to them.” Sarah also spoke of Louise being able to decipher when Sarah was feeling
frustrated with her, even though this was never mentioned. Scripting was also a strategy that Louise used. Many of the patterned interactions previously discussed were initiated by Louise. Kate also talked about how Louise planned her approach when she consulted Dave. She referred to Louise as “trying to frame her questions to him so that she won’t look crazy.” Though it was mentioned that Louise always needed to have someone with her who could translate, Kate also referred to looking for safe social situations where Louise was left to interact independently, such as at her seniors’ exercise class. In this situation, Kate described Louise’s ability to translate for others, “In her exercise class where there are people who are more disabled than she is, she is always really helpful and she’ll do the translation and she’ll do the expressing that that person can’t do.” Although Louise has a number of communication impairments and challenges, she also has the ability to utilize the same strategies for the purpose of achieving the same goals in her interactions with others.

The Concept and Context of Family

*Conceptualization of the Family*

Though the study focused on the topic of communication within the family, the conceptualization of the family was related to the family’s communication. Each participating family member was asked who they considered to be part of their family and who they considered to be part of Louise’s family. Though each individual spoke of their own family slightly differently to include their own families after marriage, there was a general consensus among the participating family members that Louise had a very broad concept of family, including many persons outside of the immediate blood
relations, “I don’t think she really has a strong boundary. She has kind of an inclusive sense. Anybody within her sphere. I don’t think she really differentiates between family and girlfriends, boyfriends, family friends.” Though this extensive concept of family was mentioned when the participants were directly asked to report who was in Louise’s family, when the family was discussed elsewhere in the interviews, reference was primarily made to Louise’s five children and her household, which included Kate’s husband Dave. Brief mention was made of Sarah’s children and Louise’s niece, Megan.

Louise was considered to be the center of the family. According to Kate, “There’s never any quibble about the fact that she’s the center of the family.” The rest of Louise’s family was conceptualized as having two parts: the core and the outskirts. Family members were positioned as either part of the ‘core of the family’ or on the ‘outskirts of the family’.

Family members that constituted the core were described as having certain commonalities. First, members of the core had what was referred to as “a direct communication pattern” with Louise. They spoke with her regularly and directly. Second, core members were referred to as having caregiving responsibilities or being able to “look after” Louise for a period of time independently. And most importantly, family members that constituted the core were identified as having interactions that aligned with the identified goals of interaction and the capability to use the strategies effectively.

The Core of the Family

There were three family members positioned at the core of the family. Each of these family members occupied a different role that entailed different responsibilities. I
interpreted these roles from the interview data as: the Expert, the Trusted Visitor, and the Silent Supporter.

Kate was the Expert. She was identified as Louise’s primary caregiver by other family members as well as herself. She managed Louise’s daily schedule, her medical affairs, and “pretty much helps her to accomplish what she wants to in the day”. She lives in the same house as Louise and had the most frequent contact with her mother. Kate described knowing Louise better than Louise knows herself and she spoke of being able to interpret her needs and her feelings with accuracy. Knowing Louise is not something new to Kate. Kate explained:

I’ve always been the one in the family that got along the best with her and understood her eccentricities and her thought patterns which a lot of people in the family are just totally frustrated with. I’m probably the most empathetic person in the family which when you’re dealing with somebody who’s as scattered as she was all her life, she just frustrated other people in the family because they couldn’t understand her, where she was coming from. But I always knew she had so much internal noise going on and she was so much not in the moment, she was always all over the place so I knew that.

Kate as the expert attempted to share her knowledge and insight with other family members. Sarah described learning from Kate, such as learning about the meaning of Louise’s giggles. Sarah said, “I think I’ve learned a lot from Kate. A lot from Kate. Watching Kate in action”. Kate also described some frustration when other family members failed to believe or appreciate her insight:

Some people in the family will watch me interact with her, think I’m being perhaps too harsh or too simple or something ‘cause I’ll speak loudly and I’ll get right in front of her and I repeat things and some people think that’s kind of insulting. But I say, ‘Well, you know, that’s where we’re at right now and if you’re not communicating with her like that I can’t guarantee that she’s going to get it.’
Kate described Louise as always having required some help getting through life. She stated, "Probably I’ve been looking after her in some aspect of daily life since I was like seven or eight years old.” As Kate had occupied a caregiving role for Louise for the majority of her life, she appeared to have mastered many of the aspects of caregiving. She offered a unique expertise on Louise’s personality, her needs, and her abilities.

Sarah was the Trusted Visitor. She lives in a different city than Louise but she spoke with her mother by telephone daily and often came to stay with her mother, especially when Kate and Dave were away. Kate acknowledged Sarah’s helpfulness and commented on her willingness to help in the provision of care. Kate explained:

Sarah is very much more involved. And can be very helpful and is working with my mom on memory stuff and going over the old stories. Other members of the family just express concern… Sarah has always been the one who would talk about ‘What do you need? When can I come over?"

Though Louise had many visitors, Sarah was a unique visitor in that she acknowledged that, as a visitor, she was not seeing the whole picture in her role as a visitor. Sarah commented, “I still am kinda visiting as opposed to living there and Kate and I talked about her seeing a different mom because they live together… There’s always that nervousness about mom that I’m visiting and she’s gotta go out of her way to make this a really special thing.” Kate also commented that Louise acted differently with a visitor, and stated:

A lot of people who visit visit for a short time. She rises to the occasion. Everything looks good. They never see her when she’s distressed. She puts on a good face. And they see her for a short time. Her energy level is good and when they go, she kind of crashes. And they don’t see that part. And so for some people it’s hard to believe.
Sarah not only recognized that she was not seeing the whole picture, but she also sought and believed information that was shared by Kate. Kate described feeling that Sarah was really “the only one” in the family that she felt comfortable having come stay with her mom. Interestingly, Sarah stated that her primary role in the family was to help Kate. She described her role as “like a respite person”. Her other role in the family was to “carry on the pretense with my mom, making everything really nice. Providing her with a life that’s so different from when she was a girl”. She clearly believed in striving towards the three identified goals in her interactions with Louise.

Dave was The Silent Supporter. Dave played a unique role within the core of the family. Living in the same house as Louise, he had regular interactions with her though they did not have conversations. Dave explained a typical interaction with Louise, “I don’t really have conversations with Louise… I go down there and I tell her ‘I’m going for a walk’ and she says ‘Okay. Have a nice time.’ And then I come back and I say ‘I’m back’ so she knows. And she says ‘Thank you. Have some muffins’ and that’s about it.” And although he struggled to interpret her non-verbal communication or the meaning behind her questions, he did buy into the three goals of interaction albeit in a somewhat passive manner. The fact that he is a male in the household entitled him to a particularly valuable role in Louise’s eyes. Kate described Louise being “heartily assured by having a male in the house”. Dave’s presence and his willingness to go along with supporting the efforts of others in achieving the goals of interaction had a significant effect on Kate’s ability to proceed with day to day life. For example, Kate described the restriction she felt in her daily life because of fears her mom had about Kate being kidnapped. She explained Dave’s somewhat passive role in alleviating Louise’s anxieties and fears:
The fact that there's a male in the house is huge. It's just huge. I cannot go out for a walk by myself in this incredibly safe neighbourhood after eight o'clock at night. I cannot go down to the store for a liter of milk. But if Dave's with me, that's just fine. I can go anywhere. I can be out anywhere with Dave.

Louise also spoke of Dave's role as someone who helped her and kept her informed of Kate's whereabouts. She described being able to call on Dave when she heard a frightening noise, such as a key trying to unlock her back door. Dave was also instructed by Kate that if Louise began to panic about Kate when she's out at night, he is to provide reassurance by reading out the message on the white board. Although Dave occupied a significantly different role than Kate and Sarah, his role as the Silent Supporter is important in their daily life. Furthermore, Dave's quietness rarely interrupted the other family members' efforts to achieve the three identified goals.

On the Outskirts of the Family

Just as some family members were situated in the core of the family, other family members were situated on the outskirts of the family. Most family members that were positioned on the outskirts of the family did not have regular communication or spend much time with Louise. Some members on the outskirts did have regular communication with Louise but were perceived as unable or unwilling to buy into the established goals or unable to utilize the strategies in order to achieve the intended goals of interaction. In some cases this inability to interact in an acceptable manner was attributed to a lack of understanding or appreciation for Louise's impairments. Kate described family members on the outskirts, stating:
With certain family members that is very hard to get through. They just don’t get it. They don’t want to see perhaps the hearing and cognitive problems she’s having. Or they are not empathic enough to understand how isolating it is. I mean Sarah and I are both well aware but we spend the most time with her. Those who spend less time are less aware. That’s all there is to it.

Family members that were positioned on the outskirts were either there by self-exclusion or they were positioned there by members of the core.

Anna, Louise’s eldest daughter, occupied an interesting role in the family, with a position just on the outskirts. Though she had regular lengthy phone conversations with Louise, she was not perceived as someone who interacted with Louise to achieve the three primary goals. Many of her conversations with Louise consisted of telling her about her “soap opera” life and “downloading everything on mom”. Louise also spoke of Anna having “had a lot of problems”. Kate and Sarah wondered if Louise enjoyed the excitement of Anna’s “soap opera” life, however they also felt that these conversations exposed Louise to a lot of worry. Anna was also perceived as someone who struggled to interpret Louise’s non-verbal communication. It was stated that Anna “will take (what Louise says) at face value even though the evidence right in front of her face is clearly to the contrary”. Further, Anna was described as someone who “has to experience for herself”. This made the sharing of insight and information difficult because Anna was perceived as reluctant to take someone’s word. Though Anna offered to stay with Louise, there was some hesitancy to accept these offers as there seemed to be a lack in confidence that Anna could keep Louise protected.

Kate and Sarah explained that their brother Jack had chosen to have minimal contact with Louise. In reference to keeping Louise’s world “nice” and enabling
everything to “run smoothly around her” Sarah stated, “My brother, he can’t be part of
that. He can’t do it. He can’t be around her.” Kate described the relationship between
Jack and Louise, referring to a long history of frustration and tension:

Mom has always said the wrong thing to him and done the wrong things
without any understanding of his personality. And he’s always
overreacted to the things she has done and said without any
understanding of her personality. So the two of them just clash on such a
basic level.

Kate provided further explanation about Jack’s self-exclusion stating, “He’s very
uncomfortable around her. I think he feels very bad about that, I know he does, but he
can’t figure out how to be in a conversation with her.” Apparently Jack could not engage
in interactions with his mother that did not entail outward frustration; he therefore
excluded himself.

Betty, another daughter, was also on the outskirts of the family. She had been
estranged from the family for apparently 25 years prior to re-connecting with the family
shortly before the study began. Betty had self-excluded for many years. Though the
researcher was not informed of the details of the events, during the study period Betty
was asked by members of the family to leave the home.

Interestingly, when asked to speak about her family, Louise referred to her family
as being “mixed up” but presented a straightforward description of her family. She did
not allude to an extensive concept of family but rather spoke of her five children and her
household. She spoke about her family when she was a child and a young adult, including
her mother who died when she was young, a step-mother with whom she did not have a
good relationship, and an unfaithful husband from whom she was later divorced. She did
seem to have an inclusive perspective when she spoke of her children and she did not
acknowledge the infrequent contact that she had with her son. She acknowledged that 
Betty was not in touch, and spoke of this as “hurting”, but she did not speak poorly of 
Betty or see her as any less of a daughter than her other children. Sarah also spoke of 
Louise’s inclusion of Betty in the family, “Mom feels Betty is very much the daughter.” 
And though Louise made no reference to certain family members being excluded, she did 
refer to members of the core far more frequently in her interview.

Contextual Issues that Influence the Family

There were two contextual issues that emerged from the data that significantly 
influenced the dynamics within the family: the shared family history and the underlying 
family rule. Though these issues infiltrated into all aspects of interactions, including the 
goals and strategies, the shared family history and the underlying family rule significantly 
influenced the conceptualization of the family.

Shared History

Participants repeatedly spoke of themselves, other family members, and 
relationships in comparison to the past. This was often done as a means of explaining or 
providing insight into their current situation. Many of the challenges that they spoke of in 
communicating with Louise were referred to as being the same challenges they have 
always experienced with her although to a different extent. On multiple occasions, Kate 
and Sarah made statements such as: “She’s always done this; this is her. It’s just more 
now.” Sarah summarizes her mother’s history of struggling to communicate:

Mom’s not been a good communicator. It’s not a totally different mom 
than it was before, just a different degree. The degree is different. It’s not
like she’s a totally different communicator. Communication with mom has always been difficult but now, with the memory and she’s got so much time on her hands, it’s just different.

Information and explanations were frequently provided to bring to light the nature of Louise’s relationships with her children. For example, the unique relationship that Kate and Louise have was discussed in relation to their history. Sarah spoke of Louise being a very different mother to Kate than she was to the rest of her children and attributes this to Kate being a different child. She commented:

Kate’s so different from every other sibling. We all have so many issues over my mom and my dad. Kate doesn’t appear to have any of these issues… With Kate mom would have fought tooth and nail to protect Kate. When we were growing up that wasn’t the mother we had; we had a doormat.

Reference was made to Kate’s long-standing role as Louise’s caregiver and, in reference to her current role as primary caregiver, Kate commented, “I think probably everyone just assumed that if someone was going to look after her it was going to be me.” The history of relationships was also sought to explain current tensions and conflicts, such as the frustration Jack felt with Louise.

Underlying Rule

There was also discussion of an underlying rule that existed, and always has existed that influenced their interactions with one another. The rule was that nothing negative or confrontational could be mentioned or discussed. And though this is similar to the notion of protecting, this idea was discussed so extensively that it seemed like less of a goal and more of a rule. According to Kate and Sarah, avoiding negative things was
a long-standing rule, imposed by Louise, which they followed. Sarah said, “Mom’s actually had this thing where we’re not to talk about the negative things.” To which Kate responded, “She doesn’t like to have negative things talked about.” Though this was perceived as Louise’s rule, there was a sense that they abided by this rule in order to both appease Louise and protect her from certain emotions, such as anger, that they felt she struggled to cope with. In discussing this, Sarah stated, “Her whole world has to be nice. Everything has to be nice. So you could never argue with mom. You could never tell her you were angry... It has to be nice. A world with no sharp edges.” Though Louise acknowledged that problems and troubles were not talked about within her family, she felt this was a conscious decision to avoid having others burdened by troubles. Louise had been discussing problems and troubles, and subsequently used the term ‘troublems’ in this statement, “I keep my problems to myself. Everybody’s got troublems, you know, in different ways. I don’t like to indulge mine on them. They’ve got equal problems.” She did not acknowledge or refer to this as being her rule. However when Louise spoke of hardships and troubling times, including abuse and adultery, she consistently ended her stories with positive statements such as, “We’re all fine now” and “So that’s the sad part of my life and everything else went fine.”

Summary of Findings

The findings in this study offer valuable insight into the research questions with a particular focus on the third research questions that refers to the experience of the family as a unit. Though not all family members participated in the study, the members that did participate discussed the broader concept of family as a unit. In this particular family, the
participating family members identified three goals that were the intended outcome of interactions with Louise and they used three specific strategies to achieve pursue these goals. In addition to the goals and strategies, the participating family members referred to the various roles and responsibilities of family members. The family was conceptualized as having family members that constituted the core of the family while others were on the outskirts of the family. Family members that were on the outskirts were by no means perceived by participating family members as excluded from the family but those on the outskirts did occupy less significant caregiving roles.
CHAPTER 5
DISCUSSION

The aim of this single family case study was to describe the family experience of communicating with a family member who has CI. Important insight into the complexity of the family’s communication experience was described by the participating family members. The voices represented in this case study describe some of the ways in which individual family members approach communication with their relative who has CI and, more importantly, how the family as a unit navigate this journey. The participating family members, all members of the core of the family, described three particular goals that were identified as the driving force behind their communication with Louise: include, protect, and bring happiness. These goals were often pursued by relying on three primary strategies in their interactions: interpreting, scripting, and translating. These strategies were often used concomitantly, just as more than one goal was often achieved in an interaction. The way in which the family was organized is a significant aspect of the family communication and caregiving experience. Though the research questions sought to capture the experience of communicating with a family member who has CI, the participants spoke extensively about the experience of communicating as the intersection of communication, caregiving, and the family.

This family illustrates the challenge of defining the concept of family. While family is frequently categorized into descriptive groups such as ‘immediate family’ or ‘step family’, in this study a distinct category evident within the family is the ‘caregiving family’. The ‘caregiving family’ consists of family members that make up the core, while
the ‘family’ includes those in the core as well as family members on the outskirts. While the ‘caregiving family’ is distinct, it is not isolated from the influence of relationships between all family members. The experience of the family affects the experience of the caregiving family and vice versa.

The vagueness of Louise’s diagnosis of CI brings to light the uncertainly and inconsistency that has been previously described in the literature (Kelley & Petersen, 2007; Robinson, Clare, & Evans, 2005; Teel & Carson, 2003). In contrast to the frustration and worry that is frequently described as it relates to the uncertainty of the diagnosis, participating family members did not refer to a desire or a need for additional information related to Louise’s diagnosis. The focus of the caregiving family seems to be negating the negative effects of the symptoms Louise is experiencing, such as memory loss, difficulty following conversation, and impaired judgment and reasoning. There was no evidence of the family’s need to explain these symptoms in relation to a disease or a disease process.

Louise’s impairments were not spoken of in isolation but the significance of her impairments was discussed in comparison to her abilities prior to developing CI. The participants repeatedly referred to themselves, other family members, and relationships in comparison to the past in order to explain or provide insight into their current situation. This study affirms the notion previously suggested by researchers and clinicians that assuming a caregiving role does not obliterate a long standing relationship (Garwick et al., 1994, Globerman, 1994; Perry, 2004; Ward-Griffin et al., 2007). For example, the relationship and the communication between Louise and Jack was described as being riddled with tension and frustration. Similar to Forbat’s (2003) research, tensions in Jack
and Louise’s relationship are rooted in their history and exacerbated by the effects of CI. In contrast, the relationship between Louise and Sarah had tensions and “issues” but rather than being exacerbated, Sarah described consciously “putting aside” these issues and changing how she communicates with her mother in order to experience a new relationship that she describes as far more satisfying. This process of re-creating the relationship is similar to Perry’s (2004) account of daughters caring for mothers as a process of deconstructing their previous relationship and reconstructing a new relationship based on new understandings.

Also relevant to the notion of shared history is the process of exclusion within the family. While members of this study were not excluded from the family, they were excluded from the caregiving family. This is similar to the findings of Globerman’s (1995) grounded theory study in which many of the participating families had a family member, termed ‘the unencumbered child’, that was excused from a caregiving role and corresponding responsibilities. Garwick and colleagues (1994) also captured a process whereby a family member was excluded, often by other family members. Interestingly, these studies are two of the few studies that examined the caregiving experience from the perspective of multiple members of the same family. As a process of exclusion also emerged from the findings of this study, which offered more than one voice for the family, one wonders whether intricacies such as exclusion from the caregiving family are inadequately captured when the family’s experience is reported by one family voice.

Further to the notion of shared history is the long standing presence in the family of an underlying rule that infiltrates all aspects of communication within the family, particularly communication with Louise. The rule that nothing negative or
confrontational can be mentioned and all interactions have to be “nice” was discussed extensively in the interviews to explain and rationalize the intricacies of communication in the family, including the rationale for the three identified goals in interacting with Louise. All participating family members spoke of avoiding confrontation and not merely as something they opted to do, but more in the context of something that had to be done. Though perceived as Louise’s rule, none of the participating family members are apparently willing to break the rule and subsequently this rule affects all aspects of communication in the caregiving family.

Significant in this study was the idea that communication within the family and the way the family organizes itself to provide care are so intricately interwoven. Previous authors have suggested that the family context, and particularly the relationships, has a significant affect in the caregiving experience (Garwick et al., 1994; Snyder, 2002). In this study, not only did the relationship affect communication, the way in which each family member communicated with Louise essentially determined their role and location within the family. The role of each family member, and the responsibilities that accompany those roles, was established based on the way in which interactions occurred. The ability and willingness to communicate with Louise in a manner that achieved the heavily weighted values of protecting, including, and bringing happiness was considered essential in order to be identified as a core member of the family. In other words, to be part of the caregiving family, a person had to interact with Louise in a particular way. Likewise, a family member’s perceived inability or unwillingness to interact to meet these desirable intentions resulted in the family member being placed on the outskirts of
the family. The family is conceptualized based on how its members communicate with Louise.

How various family members were positioned was in fact part of the family caregiving process. This was done without conversation about who would fulfill what roles. Rather it was Kate, as the primary caregiver, who was charged with the task of distributing responsibilities. She did this based on her perception of whether or not care could be provided to her mom in a protective, inclusive, and enjoyable manner. And she felt that the ability to interpret, translate, and script was essential in order to provide this level of care. If a person could not meet these care requirements, he or she was given an alternate position on the outskirts of the family. The family, communication, and caregiving were interwoven in the family experience of communicating with a family member who has CI.

Strengths and Limitations

This study has a number of strengths and limitations worthy of discussion. First, the representation of multiple family members provides valuable insight into the functioning of the family that is rarely offered in the family caregiving literature. Various aspects of the data collection process contributed to the strength of this study. The family interview provided the researcher with valuable insight into how family members spoke to each other about communicating with their relative with CI. Consensus and clarification that occurred during the family interview would likely have not been captured by relying solely on individual interviews. A second individual interview with each participating family member provided an important opportunity for participants to
be asked to comment on issues that arose during their first interview or the family interview. Additionally, including the family member who has CI allowed for the researcher to ask about the experience of communication from the perspective of the person on whom this study is focused. The researcher was able to personally experience communicating with the diagnosed family member as well as gain insight into the extent of the individual’s awareness into her impairments and the approaches her family takes to communicate with her.

The perspective of family members other than the primary caregiver that is offered in this study brings to light the value of hearing these often absent voices. This also however highlights a limitation in this study. Though many voices within the family were heard, all these voices belong to family members that were positioned within the core of the family. None of the family members that were positioned on the outskirts of the family, who presumably have a different communication experience with Louise, participated in this study. Though the researcher invited all family members to participate, this invitation was extended, or not extended to others through the primary caregiver who was the researcher’s contact. Uphold and Strickland (1993) discuss the challenge of recruiting all family members and warn of the bias that may be created when one or more family members are absent from the study. Although participation by all family members would have strengthened this study, the involvement of multiple family members provided valuable insight into the family’s communication experience.
Implications

This study has a number of implications that are relevant to families dealing with the effects of CI, health care providers, and researchers. Families are often launched on this journey of caregiving with little preparation and little time to think and plan. The advice and guidance of health care professionals is often sought to facilitate this journey, especially advice that targets communication challenges. This study brings to light the notion that communicating with a relative who has CI is not merely about what is said and how it is said. Rather the organization of the family, with members assuming various roles, is also a way families respond to the challenges of communication. In supporting and guiding families dealing with CI, health care providers need to recognize the roles within the complex network that is the family and how the family network influences the experience of each individual, including the person who has CI. Though primary caregivers play a vital role, the primary caregiving relationship is significantly influenced by the other relationships within the family. To better understand the complexity of the family caregiving experience, especially as it pertains to communication, more research that focuses on the family as a unit is needed. Understanding the experience of many different families will identify whether commonalities exist and, if so, how these commonalities can be targeted to better support families.

Conclusion

To ask the seemingly simple question of how families communicate with a relative who has CI is, in actuality, to ask a multitude of complex questions. The family, consisting of individuals but equating to far more than the sum of these individuals, is a
dynamic social network that relies heavily on communication, in all its various forms. When one family member experiences the symptoms of CI, the ‘normal’ communication within the family is not only shaken but the foundation of the family is disrupted. Roles and responsibilities change, priorities shift, and expectations of others are altered. The shaken foundation causes the family structure to adjust in various ways in order to remain as intact as possible. Ironically, sometimes fragmentation of the family may actually be a strategy that facilitates the formation of a functioning caregiving family. Where family, caregiving, and communication intersect, they do not merely provide the context but they become deeply entangled in one another.
REFERENCES


Clare, L. (2002). We’ll fight it as long as we can: coping with the onset of Alzheimer’s disease. *Aging and Mental Health, 6*(2), 139-148.


Perry, J. (2004). Daughters giving care to mothers who have dementia: Mastering the 3 R’s of (re)calling, (re)learning, and (re)adjusting. *Journal of Family Nursing, 10*(1), 50-69.


APPENDICES
Appendix A

Recruitment Letters

Letter of Information

Call For Participants

Research Project on Family Communication and Alzheimer Disease

Title of Study: Communicating with a family member who has Alzheimer disease: a family perspective

Principal Investigator: JoAnn Perry, Ph.D.
Co-Investigators: Barbara Purves, Ph.D.
Alison Phinney, Ph.D.
Lara Pollard, RN

You are invited to participate in a research study that examines family communication. The aim of this research study, which is being conducted as part of a graduate thesis, is to better understand what it is like for a family to communicate with their family member who has Alzheimer disease (AD).

The study involves participation from at least three members of your family. Your relative with AD will not be involved in this study. If you and your family members agree to participate, you will each meet with the researcher on three separate occasions at a location of your choice. First, you will be interviewed individually about communicating with your family member who has AD; this interview will take approximately 1 hour. At the end of this interview, you will complete the Perception of Conversation Index – dementia of the Alzheimer’s type (PCI-DAT), a questionnaire about communication. This will take about 15 minutes to complete. Second, all participating family members will then take part in a family interview in which you will be asked about your family’s experience communicating with your family member who has AD; this interview will last approximately 1.5 hours. During the third meeting you will complete the PCI-DAT followed by a brief interview about your thoughts on the content of the questionnaire. This final meeting will last approximately 30 minutes. Throughout the entire study you may refuse to answer any questions if you feel uncomfortable.

If you would like to participate, or you would like more information, please contact Lara Pollard at the phone number below or complete the attached form and mail it in the self-addressed, stamped envelope provided.

Contact Information:
Lara Pollard 604-786-1495
Title of Study: **Communicating with a family member who has Alzheimer disease: a family perspective**

I am interested in learning more about this study. Please contact me at the telephone number below.

Name: ____________________________________________

Telephone number: ___________________________________
Flyer

Call For Participants

Research Project on Family Communication and Alzheimer Disease

Title of Study: Communicating with a family member who has Alzheimer disease: a family perspective

Principal Investigator:  JoAnn Perry, Ph.D.
Co-Investigators:  Barbara Purves, Ph.D.
Alison Phinney, Ph.D.
Lara Pollard, MSN (c)

If you have a family member who has been diagnosed with Alzheimer’s disease (AD) and who lives in the community, you are invited to participate in a research study that examines family communication. This research is being conducted as part of a graduate thesis.

The study involves participation from at least three members of your family. Your family member who has AD will not be involved in this study. If you and your family members agree to participate, you will each meet with the researcher on three separate occasions at a location of your choice. First, you will be interviewed about your communication with your family member who has AD; this interview will take approximately 1 hour. At the end of this interview, you will complete a questionnaire about communication, which will take about 15 minutes to complete. Second, all participating family members will then take part in a family interview in which you will be asked questions about your family’s experience communicating with your family member who has AD; this interview will last approximately 1.5 hours. During the third meeting you will complete the questionnaire followed by a brief interview about your thoughts on the content of the questionnaire. This final meeting will last approximately 30 minutes. Throughout the entire study you may refuse to answer any questions if you feel uncomfortable.

If you would like to participate, or you would like more information, please contact Lara Pollard at the phone number below or complete the attached form and mail it in the self-addressed, stamped envelope provided.

Contact Information:
Lara Pollard 604-786-1495
Title of Study: Communicating with a family member who has Alzheimer disease: a family perspective

I am interested in learning more about this study. Please contact me at the telephone number below.

Name: ____________________________________________

Telephone number: ________________________________
Appendix B

Interview Guides

First Individual Interview

A. Contextual elements
   a. How are you related to (relative with AD)?
   b. Can you tell me a bit about (relative with AD)’s diagnosis and how this came about?
   c. Describe to me the living situation of your family.
   d. How frequently do you see (relative with AD)?

B. Family & Relationships
   a. Who do you consider to be your family? Who do you think (relative with AD) considers as his/her family?
   b. How would you describe the relationships in your family?
   c. Tell me about your relationship with (relative with AD).

C. Communication
   a. Can you describe a conversation with (relative with AD)?
   b. Has communication with (relative with AD) changed?
   c. Can you tell me about (relative with AD)’s ability to communicate? Does he/she have strategies to help with communication?
   d. Are there specific strategies you use in communicating with (relative with AD)? How effective are these strategies? Where did you learn these strategies?
   e. Are there ways besides conversation with you communicate with (relative with AD)? Tell me about them.
   f. Are there specific things that you find challenging in communicating with (relative with AD)? What makes these things challenging?

D. Meaning
   a. What is most important to you about communicating with (relative with AD)? Are there other things you consider to be really important?
   b. Can you tell me about a positive interaction with (relative with AD)? What made this a positive interaction?
   c. Are there any values or beliefs that you have that influence how you communicate with (relative with AD)?

E. Closing
   a. Is there anything else you would like to tell me?
Family Interview

A. Contextual elements
   a. Tell me a bit about (relative with AD)'s diagnosis and what led to this diagnosis.

B. Family & Relationships
   a. Who makes up your family?
   b. How would you describe the relationships in your family?

C. Communication
   a. Describe a typical family interaction. Where does (relative with AD) fit into the interaction?
   b. Has communication with (relative with AD) changed?
   c. Can you tell me about (relative with AD)'s ability to communicate? Does he/she have strategies to help with communication?
   d. Are there specific strategies that you use to communicate with (relative with AD)? How effective are these strategies? Where did you learn these strategies?
   e. What do you consider to be the most important aspects of communicating with (relative with AD)?
   f. Does each of you communicate in the same way with (relative with AD) or is there variation?
   g. Is communication a topic you discuss as a family? In what way?

D. Meaning
   a. Are there certain values or beliefs that influence how you communicate with (relative with AD)?

E. Closing
   a. Is there anything else you want to tell me?
Interview with Person who has CI

A. Contextual elements
   b. Who do you consider to be your family?
   c. Describe to me the living situation of your family.
   d. How frequently do you see your family members?
   e. Can you tell me a bit about your diagnosis and how this came about?

B. Family & Relationships
   f. How would you describe the relationships in your family?
   g. What is your relationship like with (each of the participating family members)?

C. Communication
   h. Can you tell me about your ability to communicate?
   i. Has your communication with family members changed? How?
   j. Are there specific strategies you use in communicating with your family members? How effective are these strategies? Where did you learn these strategies?
   k. Are there certain family members that you find it easier to communicate with? Why do you think this is the case? Are there specific things they do that help to make communication easier or more meaningful?
   l. Are there ways besides conversation with you communicate with your family members? Tell me about them.
   m. Are there specific things that you find challenging in communicating with your family members? What makes these things challenging?

D. Meaning
   n. What is most important to you about communicating with your family members? Are there other things you consider to be really important?
   o. Can you tell me about a positive interaction with a family member? What made this a positive interaction?
   p. Are there any values or beliefs that you have that influence how you communicate with your family members?

E. Closing
   q. Is there anything else you would like to tell me?
Appendix C

Consent Forms

Consent Form for Family Members

Consent Form
Communicating with a Family Member who has Alzheimer Disease:
A Family Perspective

Principal Investigator:
Dr. JoAnn Perry, School of Nursing, (604)822-7496

Co-Investigators:
Dr. Barbara Purves, Faculty of Speech and Audiology
Dr. Alison Phinney, School of Nursing
Ms. Lara Pollard, School of Nursing

Purpose:
The purpose of this study is to learn more about how families communicate with a
family member that has Alzheimer disease (AD). This study is part of a nursing
graduate thesis. You are being asked to take part in this study because a person in
your family has AD. As the study is looking at the family unit, at least three
members of your family must agree to participate in this study. However, if a family
member chooses to withdraw from the study prior to its completion, the remainder
of the family will not be excluded from the study.

Study Procedures:
If you and at least two other family members agree to take part in this study, Ms.
Pollard will meet with you three times. Two of those visits will be with you on your
own. One visit will be with all of your family members that are participating in the
study. All the visits will be at a time convenient for you at a location of your choice.

During the first visit with Ms. Pollard, she will meet with you by yourself to ask a few
questions about your communication with your family member who has AD. This
interview will be audio recorded and will last about one hour. Ms. Pollard will be
interviewing each member of your family involved in the study. At the end of this
interview, you will be asked to complete a questionnaire about communicating with
your family member who has AD. The completed questionnaire will be mailed to
Ms. Pollard.

During the second visit with Ms. Pollard, all family members involved in the study
will get together to talk to Ms. Pollard as a family about communicating with your
family member who has AD. As with the first interview, this visit will be audio
recorded and will last about one hour.
The final visit with Ms. Pollard will be a brief visit where you will be asked to complete the same questionnaire about communicating with your family member who has AD. Ms. Pollard will then ask you some questions about the questionnaire. This will take about half an hour.

At the beginning of each visit, you will be asked if you are still willing to take part in the research project.

Risks and Benefits:
There are no known risks associated with participating in this study. The potential benefits include learning more about the communication you have with your family member who has AD and the communication within your family.

Confidentiality:
To ensure confidentiality, a code number will be used to identify you in the study’s data. Your identity will be kept confidential. It may be difficult to keep your family anonymous to people that know your family, however you and your family members will be repeatedly consulted to ensure you are comfortable and agreeable to the potentially identifying information in the graduate thesis and any other final material.

The information you provide during the individual interviews and within the PCI-DAT questionnaire will be kept confidential. Prior to the family interview, the researchers will discuss with all participants the importance of being aware and respectful of the sensitive nature of the information being shared. Though the researchers cannot guarantee confidentiality of the information shared within the family interview, as one family member may refer to what another family member shared outside of the group, the researchers will emphasize the need for all participants to be respectful of each others privacy.

This consent form will be kept in a locked place separate from all other study data, and all documents and recordings will be kept in a locked office and/or on a password-protected computer. Only Ms. Pollard, Dr. Perry, Dr. Purves, and Dr. Phinney will have access to these documents.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact Dr. JoAnn Perry at 604-822-7496.

Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without affecting your access to related services.
Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Participant Signature       Date

Printed Name of the Subject signing above.
Consent Form for Person who has CI

Consent Form
Communicating with a Family Member who has Alzheimer Disease: A Family Perspective

Principal Investigator:
Dr. JoAnn Perry, School of Nursing, (604)822-7496

Co-Investigators:
Dr. Barbara Purves, Faculty of Speech and Audiology
Dr. Alison Phinney, School of Nursing
Ms. Lara Pollard, School of Nursing

Purpose:
The purpose of this study is to learn more about how families communicate with a family member that has Alzheimer Disease (AD). This study is part of a nursing graduate thesis. You are being asked to take part in this study because you have a diagnosis of cognitive impairment. As the study is looking at the family unit, at least three members of your family must agree to participate in this study. However, if a family member chooses to withdraw from the study prior to its completion, the remainder of the family will not be excluded from the study.

Study Procedures:
If you agree to take part in this study, Ms. Pollard will meet with you once at a time and location of your choice. During this time, Ms. Pollard will meet with you by yourself to ask a few questions about your communication with your family members. This interview will be audio recorded and will last about one hour. Ms. Pollard will be interviewing each member of your family involved in the study.

Risks and Benefits:
The potential benefits include learning more about the communication you have with your family members and the communication within your family. The potential risks include possibly feeling sad when discussing some of the challenges you experience when communicating with your family members.

Confidentiality:
To ensure confidentiality, a code number will be used to identify you in the study's data. Your identity will be kept confidential. It may be difficult to keep your family anonymous to people that know your family, however you and your family members will be repeatedly consulted to ensure you are comfortable and agreeable to the potentially identifying information in the graduate thesis and any other final material.

The information you provide during the individual will be kept confidential. This consent form will be kept in a locked place separate from all other study data, and all documents and recordings will be kept in a locked office and/or on a password-
protected computer. Only Ms. Pollard, Dr. Perry, Dr. Purves, and Dr. Phinney will have access to these documents.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact Dr. JoAnn Perry at 604-822-7496.

Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without affecting your access to related services.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Participant Signature                Date

Printed Name of the Subject signing above.
CERTIFICATE OF APPROVAL - FULL BOARD AMENDMENT

PRINCIPAL INVESTIGATOR: JoAnn Perry  
DEPARTMENT: UBC/Applied Science/Nursing  
UBC BREB NUMBER: H06-03964

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

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Other locations where the research will be conducted:
Research will be conducted at a location of the participants' choice. This may include the participants' homes, at an office in the School of Nursing, or any other location of their choice that will offer a relatively quiet environment.

CO-INVESTIGATOR(S):
Larissa Pollard  
Alison Phinney  
Barbara A. Purves

SPONSORING AGENCIES:
Alzheimer Society of Canada

PROJECT TITLE:
Communicating with a family member who has Alzheimer disease: a family perspective

Expiry Date - Approval of an amendment does not change the expiry date on the current UBC BREB approval of this study. An application for renewal is required on or before: March 20, 2008

REB MEETING DATE:  
September 27, 2007

AMENDMENT(S):

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AMENDMENT APPROVAL DATE:  
December 3, 2007
The amendment(s) and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair