

Running head: ACCOMPLISHING LIFE TOGETHER

The Couple Living with Dementia in the Community:

Accomplishing Life Together

Through their Efforts toward Mutuality

by

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A Thesis submitted to the Faculty of Graduate Studies of The University of Manitoba

in partial fulfilment of the requirements of the degree of

Doctor of Philosophy

Applied Health Sciences

University of Manitoba

Winnipeg

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### **Abstract**

The relationship of the couple when one spouse lives with dementia is increasingly identified as significant to their experience of dementia. My study explores the couples' relationship by examining their efforts toward mutuality. Two research questions were developed to explore the couples' efforts toward mutuality: 1. How did the intimate couples respond to each other when they were talking about their everyday activity/ relational story and when they engaged in routine/novel activities; 2. How did their responses shape the mutuality of the intimate couple? Focused ethnographic methods were used to collect the data. Three to five field visits were conducted with eight different couples. Data was collected using joint, individual, semi-structured and guided conversation type interviews and participant-observation. Symbolic Interactionism and the narrative approach informed the thematic analyses applied to the data. Answering the first question identified how the social self of the PLWD and their spouse were making sense of their current situation living with dementia. Two types of responses were identified: the response of the familiar self and the response of the unfamiliar self. The response of the familiar self expressed the spouses moving toward mutuality while the response of the unfamiliar self expressed the spouses difficulty with their mutuality. The second question was answered by deciphering the patterns of responses in the stories being told by the couple. These responses formed three different patterns of interactions. These different styles of interaction are enhancing, maintaining and disrupting. The different responses and styles of interactions are the analytical framework that describes the mutuality being expressed in the interaction. The findings of this study identify that the couple makes meaningful efforts toward mutuality to accomplish their life together. It is suggested that strategies promoting the well-being of the couple be based on principles of relational practice.

### **Acknowledgements**

There is a community of people that have supported me in my journey towards completing a Doctorate in Applied Health Sciences. I extend my deepest gratitude to my thesis advisor, Dr. Lorna Guse. Dr. Guse's commitment to research that benefitted the understanding of the older adult was a strong value that reinforced my perseverance when the road became a little rocky. Her guidance has been steadfast and encouraging.

I am also acknowledge and am grateful to the couples that participated in my study. It was appreciated that they opened their homes and their hearts in their conversations with me.

I am thankful to my internal committee: Dr. Donna Martin, Dr. Kerstin Roger, and Dr. Laura Funk. I learned about the application of theory, the analysis of qualitative data and the writing process from them. I appreciated the detailed attention they provided when reviewing the final drafts of my thesis. Their input was invaluable and contributed to the clarity of the thesis. I appreciate the time that Dr. Donna Martin took with me to review my initial transcripts. This gave me confidence to move forward in data collection and analysis. I appreciate the time Dr. Kerstin Roger took to review my analysis. Her reflections on some of my data broadened my thinking about my analytical process. I am very grateful for the time Dr. Laura Funk spent time talking to me about application of theory. The questions she asked when I discussed my findings with her contributed to my analytical insights. I also thank my external examiner, Dr. Jennifer Baumbusch for her thoughtful review of my study. My reflection on these questions added to my understanding of scholarly inquiry.

I acknowledge and express my heartfelt thank you to Diane Capanec and James Plohman who worked for the Manitoba Centre for Nursing Health Research (MCNHR). The MCNHR was responsible for administering the Fort Garry Legion Poppy Fund I attained and for providing

practical support in the development of figures, charts and posters. I thank the Fort Garry Legion Poppy Trust Fund for their financial support. I am thankful to the Canadian Gerontological Nursing Association for awarding me the Anne C. Buckingham Scholarship. I am grateful for the support provided by the Alzheimer Society of Manitoba in recruiting couples for my study. I am also thankful for Norma Kirby's (the Program Director of the Alzheimer Society of Manitoba at the time) review of my process for recruiting couples for my study.

I appreciate the Applied Health Sciences program for the encouragement they have provided while I have been in the program. I am thankful for their administrative and travel support.

I am humbled and grateful for the large number of people outside of the academia community who have both challenged and supported me on my journey to complete a dissertation. Most of all I acknowledge and am thankful to my husband, Ross Tallman and my children, Adam, Jacob and Alyson Tallman, who I always knew were there for me.

**Quote and Dedication**

To my parents: Gail and John Adamson

**An Ancient Aztec Prayer:**

Oh, only for so short a while you

have loaned us to each other,

because we take form in your act

of drawing us,

And we take life in your painting us,

And we breathe in your singing us,

But only for a short a while,

Have you loaned us to each other.

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## Chapter 1: Statement of the Problem

*“I grieve every day for the losses my husband and I experience with the changes in dementia. Well you know what I, I’ve been advised when Arthur first went into, into supportive housing, don’t visit too often. For god sake don’t take him home! It will just upset him. You know I, I can’t live like that and I can’t, I just can’t. I still love him very much and I still like to have him around. This is not to say that we do not also experience the joy of living.”* (Anonymous, 2016)

Dementia is a chronic, progressive syndrome causing significant disability and high human and economic costs (World Health Organization, 2017). The above excerpt illustrates how the person living with dementia (PLWD), Arthur and his wife struggle together to continue their relationship. Most people living with dementia are and will be cared for by family members living in the community (Braun et al., 2009), including spouses or other intimate persons. Support of family members who are caring for a PLWD is associated with delayed institutionalization of the PLWD (Mittelman, Haley, Clay, & Roth, 2006).

Dementia is a public health priority (World Health Organization, 2017). The current number of Canadians (565,000) living with dementia is anticipated to double by 2031. Currently, 1.1 million Canadians are affected directly or indirectly by the disease. By 2040, the estimated cost of dementia care will be \$293 billion per year (Alzheimer Society of Canada, 2018). There is no medical cure in the foreseeable future for dementia (Chaufan, Hollister, Nazareno, & Fox, 2012). A medicalized perspective to understanding dementia can impose a way of thinking that reduces the value of a continuing relationship with a PLWD (Moser, 2011; Seaman, 2018). Recognizing this, the World Health Organization identifies the need to promote quality of life and well-being in both PLWD and those who are in their lives to help and support them to live comfortably day to day.

Empirical studies identify the significance of intimate relationships for health outcomes for PLWD and those who are intimately involved such as their family members (Ablitt, Jones, &

Muers, 2009; Norton, Østbye, Smith, Munger, & Tschanz, 2009). In one study, spouse carers presented symptoms of depression that included feelings of loss of a sense of intimacy, shared activities and shared understanding with the PLWD (Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010). Qualitative researchers have identified that interactions occurring within couples influence the couple's perception of the dementia experience (Robinson, Clare & Evans, 2005; Svanstrom & Dahlberg, 2004; Wadham, Simpson, Rust, & Murray, 2016). One intervention study, aimed at improving cognitive function, reported that improvements also occurred in the quality of the relationship between the PLWD and their spouse (Quayhagen & Quayhagen, 1996). Collectively, these studies demonstrate the significance of the relationship in the context of dementia.

Indeed, a deeper understanding of the couple's relationship may improve the clinical outcomes of the PLWD and spouse (Chan, 2011; Watson, Tatangel, & McCabe, 2018). According to Behuniak (2010), a relational lens that incorporates acknowledging the couple's "human connectedness, commonality and interdependence" (p.70) is needed. However, we still know little about how to best understand and incorporate a couple's relationship into clinical practice (Balfour, 2014). Barriers to attending to the relationship are the result of the "false dualism of a simple carer-care receiver relationship" (Graham & Bassett, 2006, p. 336). Further research is needed to develop concepts and models that describe the dynamics of this relationship to guide policy, program and service provision.

Concepts that describe the relationship within the context of dementia redirect attention away from a medicalized perspective which tends to be "harmful and deeply damaging to the person with dementia" (Kitwood, 1997, p.46). Medicalized interventions focus on the losses or disability of the PLWD and can contribute to a sense of lost humanity or self (Karner & Bobbitt-

Zehr, 2005; Kontos, 2004, 2012). Medicalization also imposes the view that there could be an ideal world in which dementia no longer exists. This leaves people in close relationship with the PLWD feeling less valued in their efforts to make a good life with the PLWD (Moser 2011; Seaman, 2018).

The personhood concept is a critical response to the medicalization of dementia (Kitwood & Bredin, 1992). Personhood addresses the social-psychological situation that can influence the clinical manifestations of dementia. Kitwood (1993) identifies that the clinical manifestations of dementia involve the complex interactions of a person's personality, their biography, their physical health, their neurological impairment and their social psychology. The social-psychological situation is manifested in the everyday life including interactions that make up the person's life. The interaction has the potential to enhance or diminish the person with dementia's "sense of safety, value and personal being" (Kitwood, p. 67). The personhood concept clarifies those interactions in which the PLWD incorporates "that relationship is primary" (Kitwood, 1997, p.10). Personhood "is a standing or a status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, p. 8).

In an interaction in which personhood is conveyed to the PLWD, there is a sense that the person talking to the PLWD is responding to the humanity of the PLWD. Those interactional qualities that convey personhood are discussed by Kitwood. Kitwood (1997) applied Burber's ideas about the 'I-thou' or the 'I-it' relationship to distinguish interactions that bestow personhood within the interaction and those interactions that do not bestow personhood. In the 'I-it' interaction, the person keeps a safe distance, avoids risks and exposing their own vulnerability to the PLWD. When relating to the PLWD as a 'thou' on the other hand, the person is "going out towards" the PLWD. Clarifying how this needs to be expressed within the

interaction Kitwood describes positive person work which are said to “strengthen positive feelings, nurture ability or help to heal psychic wounds” (p. 89). Communication strategies that promote the social value of PLWD are discussed in other early dementia care literature. These approaches include a calm reassuring manner, humour, requesting assistance from the PLWD, and building a sense of familiar (Kitwood, 1997; Taft, Fazio, Seman, & Stansell, 1997).

Descriptions of interactions which support the personhood of PLWD do not consider the cultural context of the PLWD and their spouse or family member. The framework of relational ethics recognizes that the cultural context shapes the way the health care provider engages with patients and their families (Bergum & Dossetor, 2005). In this framework health care providers are encouraged to incorporate an awareness of “the broader social and structural context” in which patients and families respond to their condition (Wright, Brajtman and MacDonald, 2018, p. 3). Recognizing how broad social and structural context of dementia for the intimate couple can shape how the intimate couple’s interact or relate to each other can potentially enhance the support provided to the PLWD and their spouse.

The interaction between the intimate couple can be a venue for understanding the context of dementia for the intimate couple. Dementia can interject the unexpected into previously well-established ways of relating for the intimate couple. A relational lens attends to the reciprocal nature of the interaction between a PLWD and their family carer (Braun et al., 2010). The concept of intersubjectivity attends to the quality of human relatedness in which one person attends to the other to bring meaning to the circumstances they are encountering in life. Intersubjectivity is the foundation on which humans have developed language and other symbols to facilitate their ability to connect and share their understanding of the world (Duranti, 2010). It recognizes the bi-directional nature of interaction that creates culture or a way of living in this



world with others (Prus, 1996). The concept of intersubjectivity can help us better understand the relationship between the PLWD and their carer and can help us understand the everyday struggles of the PLWD and their carer (Molyneaux, Butchard, Simpson & Murray, 2012; Teunissen, 2014).

Prus (1996) describes the practical application of the concept of intersubjectivity to the study of human relations where intersubjectivity is observed in people's efforts toward mutuality, such as taking the "minds of others" (Dietz, Prus, & Shaffir, 1994, p.14) and pursuing common or shared understanding through language and images (Dietz, Prus, & Shaffir). Coming to some sort of shared understanding or mutuality is the accomplishment of group life. This accomplishment fosters bonds and the pursuit of everyday activities. Ongoing everyday activities are dependent on mutual understanding, on the iterative process that occurs within interaction to sustain the meaning and purpose of the activities (Dietz, Prus, & Shaffir; Seaman, 2018). Intersubjectivity is accomplished or constructed and it is revealed through the efforts toward mutuality within interaction (Prus).

Studies applying a relational approach shed light on how the relationship of the couple living with dementia influences the interactions with each other and the experience of dementia. Some studies have focused solely on the experience of the 'carers' of the PLWD (Galvin, Todres & Richardson, 2005; Perry & O'Connor, 2002) and a few focus on the PLWD experience in relationship (Clark et al., 2010; MacRae 2010, 2011). Increasingly studies describe how couples live with dementia (Beard, Sakhtah, Imse, & Galvin, 2012; Fletcher, 2018; Graham & Bassett, 2006; Hellström, Nolan & Lundh, 2007; Johnston & Terp, 2015). Few studies have tried to acquire an understanding of how the interaction between the couple responds to the changing nature of dementia (Tolhurst, Weicht & Kingston, 2017). Research is needed to understand how

couples adjust within interaction to accomplish everyday life in their changing circumstances of dementia. Exploring efforts toward mutuality provides insight into the couples' relationship within the context of dementia.

### **Study Purpose and Research Questions**

The purpose of this study is to explore efforts toward mutuality among intimate couples. The intimate couple is comprised of spouses who live in the community. One of the spouses of the intimate couple has dementia and the other one does not have dementia. Exploring the efforts toward mutuality involve examining the individual responses occurring within an interaction and interpreting the meaning of these responses:

### **Research Questions**

The following questions explore the efforts toward mutuality among intimate couples living with dementia:

1. How do intimate couples living within the context of dementia respond to each other:
  - a) While discussing everyday activities and describing their relational story and;
  - b) While interacting during routine activities and novel activities;
2. How do the responses of the intimate couple shape their mutuality as a couple living within the context of dementia?

### **Philosophy and Theory**

Qualitative research is based on the philosophical assumption that reality is subjective and the researcher has views and values that inform the study. The application of the philosophical assumption of qualitative research leads to inquiries that facilitate understanding the participant's reality (Creswell, 2007). Meeting the objectives of these philosophical assumptions involves the researcher becoming close to the participant so the researcher can

better understand the participant's reality. I describe the assumptions of the interpretive stance, the theory of symbolic interactionism (SI), and the narrative approach that guide the methodological approach of my study.

### **Interpretive Stance**

The interpretive stance assumes that “meaning is constructed via the interaction between humans or between humans and objects” (Hesse-Biber & Leavy, 2011, p. 17). The researcher interprets the meaning people have about their interactions, their activities and objects.

Prus (1996) describes interpretivism as acknowledging that people are engaged in meaning-making as they undertake their daily life. People apply meaning to objects and things that are based on historical and social norms. This does not mean that meaning is reproduced from one person to another but rather that it is produced in the interaction and conversations people have with each other. The researcher gains insight about people's meaning of objects and things inductively, by being with them.

### **Symbolic Interactionism**

The theory of SI assumes that people come to a “shared linguistic or shared reality” (Prus, 1996, p.15) to sustain their group life. This shared reality comes about through the human ability to construct “shared linguistic or symbolic reality that takes its shape as people interact together” (Prus, p. 15). Symbolic interactionism (SI) considers how “images take their shape and become transformed” (p. 49) and how new understandings of previously understood situations develop and become more commonly shared. According to SI, transformation of understanding is dependent on the “human quest for intersubjectivity or mutuality of understanding” (Prus, xvii).

Hewitt and Shulman (2011) describe what is meant by meaning in symbolic interactionism. A symbol is a “vocal or other types of gestures that arouse” (Hewitt & Shulman, p. 33) the same meaning in the person who is using it as in the person to whom it is directed. How we name or understand social objects including self is “central to the way ‘we’ approach the world” (Hewitt & Shulman, p. 27). People then ‘act’ towards that object in accordance with the name or meaning that has been applied (Blumer, 1969). Blumer describes the assumptions of SI: human beings act toward things on the basis of the meanings they have for these things; the meanings of things arises out of social interaction that one has with others; and meaning is modified through an interpretive process.

Blumer’s theory suggests that when people are exposed to unfamiliar circumstances people actively rename social objects. In the renaming of social objects people come to understand social objects in ways that align with the goals that they have in their particular circumstances and settings. Mead (Blumer & Morrione, 2004) discusses the self as a social object that is understood in the social interaction. Each person responds to a social situation by adjusting the meaning of to fit into their life situation. Self is formed and results in the self adhering to “norms, values, carrying out roles, living up to the demands of their status position, or conforming to cultural definitions” (Blumer & Morrione, p. 17). Social interactions are the way people create new understanding, including a new way of naming the social object (i.e. another person, themselves). For example, a spouse might start describing themselves as the “caregiver” of their spouse with dementia (O’Connor, 2007) shaping their everyday responses and interactions.

SI assumes that meanings of self can be created or re-created in interaction (Prus, 1996). SI suggests that people’s behaviour changes in different situations because of the meaning that

things have for them (for example, the meaning of dementia). The researcher's application of SI involves observing changes in behaviour of participants in the interaction. The researcher interprets these changes as reflecting a change in the meaning of something for the participant (Hewitt & Shulman, 2011).

Responses express the adjustment or observable behaviour of self's process of meaning-making or interpretations of the social environment (Hewitt & Shulman, 2011, p. 61). People in social interaction experience an "urge to act-to respond in some way to the other" (Hewitt & Shulman, p. 40). People respond by interpreting the meaning of the gestures (Blumer, 1969). Responses as acts occurring within the interaction can represent the "ongoing interpretive, adjustive process, consisting of people making indications to one another, interpreting the indications that others make and adjusting one's own definition and behaviours of these interpretations" (Dietz, Prus, & Shaffir, 1994, p. 16). Responses are "iterative adaptation to the ever-changing, ever-new, and consequently more or less unforeseeable behaviour displayed by others" (Flaherty, 1990, p.94). These adjustments include the meanings that "self has made about self" (Blumer, 1969, p. 2).

In applying the premises of SI, my study directs attention to how self is being expressed within the interaction. Studies have applied these premises to understand the interaction of the PLWD (Clarke et al., 2010; MacCrae, 2010). In these studies, it is interpreted that the meaning of self in the interaction is responding to the social interactions encountered by the PLWD. Clarke et al. identify that PLWD come to see themselves as less desirable in interactions because there is risk involved in when others respond to their cognitive impairment. MacCrae identifies that PLWD have a sense of self that can be maintained by those intimately involved with them despite information from others that they have changed. In these studies interpretation by the

PLWD has implications on meaning of self in relation to the dementia diagnosis. SI has primarily been applied in studies in which PLWD have language abilities that can facilitate the expression of self. Applying this theory to interpret the meaning of self makes is difficult when the language ability of PLWD is compromised. This study is an inquiry into each spouse's efforts to attend to the other in the context of dementia including language changes. The limitations of possible language difficulties are understood in the context of the interactions of the spouse. Additional insight into how the couple attends to each other is gained through the narrative approach.

### **Narrative Assumptions and Approach**

Applying the narrative approach to understanding what is happening in the interaction between the PLWD and their spouse brings attention to not simply what is being said but “how it is said in the context of shifting roles of speaker and listener (interpersonal)” (Riessman, 1993, p. 21). It considers how each person in the interaction is making sense of self and bringing a sense of continuity to self in their responses to the other.

SI's assumptions direct attention to the changes people make in their interpretation of the meaning occurring in the interaction. Responses are the observable behaviour of these changes. The narrative assumptions suggest that the observable behaviours of people are expressed by self in their narrative. Narrative assumptions further clarify the process people undertake in the interaction to bring order to themselves (De Medeiros, 2014). It is assumed that the stories that are told, their order, their structure-including how they engage or do not engage-is bringing order to self. Narrative assumptions are that the temporal organization of what is being said by each person has some purpose in that it holds some meaning for the speaker. For example, narrative assumptions are applied to understand how people bring order to disordered lives especially for

“individuals facing biographical disruption of chronic illness” (Riessman, 1993, p. 3). Narrative assumptions that guide the narrative approach describe that self brings order by externalizing social ideals about self to create a “retrospective consistency at any given point in time” (De Medeiros, 2014, p. 38).

Applying this approach to understand interaction provides insight into how people move from chaos to order through transposing their values and sense of continuity within their stories. Thus, created narrative is a “form of social action that is shared within a certain context that makes self observable to others” (Sparks & Smith, 2008, p. 299). De Medeiros (2014) defines the relational self or that self that brings continuity to the narrative as the self addressing these three questions within the interaction: “Who am I?; How do I know who I am?; How do you know who I am?” (p.38). The relational self is being expressed in the narrating process (De Medeiros).

Narrative assumptions link the theory of SI and the interpretation of people’s sense making as efforts toward mutuality within the interaction (Ezzy,1998; Gubrium & Hostein, 2008). SI posits that people make sense of their lives by adjusting their understanding or meaning of themselves or their circumstances. They make efforts toward mutuality (Prus, 1996). In the process of narrating, people make sense of their lives, and by making sense of themselves they are more understandable to the other (Sparkes & Smith, 2008). For example, a person’s interjection into an interaction (or in their process of narrating) that they were a ‘farmer’ reflects ‘who they know they are’ and ‘how they know who they are’. The sense making process made by the comment is made clear in understanding how being a ‘farmer’ brought a sense of coherence to that person’s understanding of self in the context of the interaction. By making who

self is clearer in the interaction, the relational self is making efforts toward mutuality in the interaction.

In my study, I apply the assumptions embedded in the interpretive stance, in the theory of SI and in the narrative assumptions to understand efforts toward mutuality interaction expressed in the interaction between the PLWD and the spouse. These assumptions of SI and the narrative structured my inquiry. Focused ethnographic methods helped me gain insight into the meanings created by the PLWD and their spouse in their interactions.

The interaction of the couple identifies how people adjust or not to the changes in their shared understanding as it relates to their context of dementia. Several definitions of concepts are pertinent to understanding a couple's efforts toward mutuality in the context of dementia.

### **Definitions**

The following definitions are relevant to my study exploring the efforts toward mutuality among the intimate couple.

**Dementia:** "Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain their activities of daily living. Alzheimer disease is the most common form of dementia and may contribute to 60–70% of cases. Other major forms include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are indistinct and mixed forms often coexist." (World Health Organization, 2017, p. 3).

**Context of dementia:** "Contexts are multiple and layered or nested" (Schrauf, & Iris, 2014, p. 29). The context of dementia is the circumstances in which the intimate couples



are currently living, for example, how common values and past ways of relating and sharing an understanding of events and activities are an aspect of current or present interactions.

**Everyday activity:** Activity is the focus of “meaningful human behaviour” (Prus, 1996, p. 16). Everyday activities include the usual shared activities by the couple such as meal making, walking, and conversing, problem solving, decision making, and conflict management (Hasselkus & Murray, 2007). Everyday activities are the accomplishment of interaction and are a result of the process of establishing or maintaining mutuality (Dietz, Prus & Shaffir, 1994).

**Relationship:** A bond that one person has with another person that selectively organizes their efforts toward mutuality with that person. People are group oriented and “develop more particular bonds with one person than with another” (Prus, 1996, p.16). People depend on those with whom they are more selectively bonded to understand how self fits into society. This encompasses the idea that people are communal and orient themselves to others, especially those with whom they are bonded to understand how self fits into society (Prus, 1996).

**Carer:** The person who supports the PLWD to live and manage daily life. In my study the carer is the spouse.

**Intimate couple:** For my study, the intimate couple consists of spouses; one who has dementia and the other who does not have dementia.

**Spouse:** The person who is married to the PLWD.

**Response:** An element of the interaction between two people in which one person acts towards another. The response is the controlled observable behaviour that integrates the

internal state of the person and external situation (including the response of the other) (Hewitt & Shulmann, 2011).

**Interaction:** The social activity in which people respond to one another. People respond within the interaction to achieve their goals (Hewitt & Shulmann, 2011).

**Efforts toward mutuality:** Meaningful interactions in which people use their “self-reflectivity and minded behaviour” (Prus, 1996, p. 13) to reach their goals. Minded behaviour describes how people take each other into account in their actions (Blumer & Morrione, 2004). It is through this social process of adjusting within the interaction that people come to a shared understanding about the meaning about self, actions and relationships. Shared understandings are established in ongoing everyday interactions (Hayes, Boylstein, & Zimmerman, 2009).

**Mutuality:** The extent of shared understanding created between people in an interaction (Prus, 1996, p. 16). The style of relating is described as a “shared understanding” (Prus, p. 16) when each partner’s goal is being met in the interaction.

**Self:** The social self and the relational self are both applied to understanding the efforts toward mutuality of the intimate couple (Blumer & Morrione, 2004). The social self refers to how the self is adapting and being formed in the interactive process (Blumer & Morrione,). Mead’s social self is linked to relational self in the narrative process (Ezzy, 1998; Gubrium & Holstein, 2008). The relational self reflects the adjustment in the narrative by bringing a sense of order or sense of continuity to self within the context of the interaction occurring everyday activity. It is the actions of the relational self within the narrative that bring a sense of coherence to self.

### **Significance of the Study**

My study is significant because it generates knowledge in the complex and understudied phenomena of the relationship of the intimate couple. Assisting the intimate couple to live in their circumstances of dementia is aided by shifting clinical practice from a medicalized practice to relational practice. My study explores their relationship by considering how each person in the couple is making efforts toward mutuality. In focusing on efforts toward mutuality, to try to understand the interaction, I consider how each person's attention to the other influences their everyday life.

Medicalized practice individualizes dementia because it describes the diagnosis as occurring to just one person. The PLWD is understood to have a set of symptoms that express the pathology of brain. A social response to the potential symptoms and losses emphasize the PLWD growing incompetency and dependency and contributes to the stigma, referred to as dementiaism (McParland, Kelly & Innes, 2017). The continued ability of PLWD to express connection to others has been observed during interaction (MacRae, 2010). Interaction is the venue in which the interacting pieces of the social attitudes of dementia, the neurological changes of dementia and the bond of the couple can be explored.

The relational approach emphasizes the value of relationship in the everyday lives the PLWD and those people who are supporting them. I am exploring how the couples try to understand each other and their circumstances. This approach is different from other approaches that explore how individuals and couples live with loss, disability and disconnection in relationship. My study can lead to principles on how to implement relational practice through policy, programming and clinical care by recognizing the difficulties of living with dementia through fostering the strengths of the intimate couple.

### **Summary**

Chapter 1 provides the statement of the problem, study purpose and research questions, philosophy, and theory, definitions, and the significance of the study. Chapter 2 reviews empirical studies that emulate our current understanding of the intimate couple's experience of dementia. Chapter 3 describes the methods used to collect and analyze data for my study. Chapter 3 also describes the rigor of the study including alternative methods. Chapter 4 and Chapter 5 present the findings of the study. Chapter 4 describes findings that answer research question 1. Chapter 5 describes findings that answer research question 2. Chapter 6 discusses how the findings of this study fit into the current research exploring the experiences of couples living with dementia, relational practice implications and future research.

## Chapter 2: Literature Review

My literature review is guided by qualitative research taking a relational approach to intimate couples. A relational approach studies how the “human need to continually be in relationship” (Merrick, Camic & O’Shaughnessy, 2016, p. 35) shapes the context of dementia. People’s actions that reflect their need to be in relationship are their efforts toward mutuality (Prus, 1996). Mead’s description of the social self emphasizes how the efforts toward mutuality by the intimate couple are linked to how they understand they fit into society: “Self develops and takes its shape as people take the role or assume the perspective of the community at large” (Dietz et al., 1994, p. 14). Research about how the social self of the carer and the PLWD separately respond in interaction contributes to understanding the interaction. Few research studies directly examine intimate couple’s interaction. Of these, there is often a general description of their interaction but little explanation about how the study captured the interactive features (Torgé, 2013). Primarily, my review focuses on studies that have interpreted the interactions of the intimate couple.

I used the search engine ‘Scopus’ and ‘CINHAL’ to uncover the literature on the relationship of the intimate couple. The initial keywords used were ‘intersubjectivity’ and ‘mutuality’ with ‘dementia’. In 2014, there were no studies identified with these key words. Other key words included: ‘relationship’ ‘interaction’, ‘communication’ ‘couple’ and ‘couplehood’ with ‘dementia’ to search the databases. On the advice of a committee member I reviewed websites that were centres of research of dementia (eg. Centre for Research on Personhood with Dementia in B.C.) to seek relevant research. Reference lists and bibliographies were used. I also used search engines to look for research conducted by specific researchers known for their work in the area, for example, Keady, Purves, Phinney and O’Connor.

In this chapter I present research using the relational approach that conveys pertinent findings on the relationship of the intimate couple. In the first section of this literature review I present research that describes how the context of dementia is seen to shape the expression of the social self of the carer and the social self of the PLWD in their relationship. In the second section, I describe how the concept of personhood has been applied in studies examining the interaction of the intimate couple. In the third section, I present studies that describe the dynamics of couple's interactions, I examine how studies explore the couples' interaction and I review how understanding the interaction offers insight into the relationship of intimate couples.

### **Studies Describing the Social Self of the Carer and the PLWD**

In this section, I present studies on social self of the carer and the social self of the PLWD as described in research.

#### **The Carer and the Social Self**

The relational approach considers how the social self of the carer responds to the context of dementia. Carers express uncomfortable emotions associated with their changes in their interaction with the PLWD (Galvin, Todres & Richardson, 2005; van Wijngaarden, van Der Wedden, Henning, Komen & The, 2018). Galvin et al. (2005) provide a narrative describing a husband's entire journey caring for his wife living with dementia. The initial theme 'something is wrong' captures the various interactions that occurred in response to things not going how they used to go in everyday activity prior to diagnosis. Similar to this theme found by Galvin et al. (2005), a more recent study that interviewed 46 carers found that prior to the diagnosis of dementia, carers had "growing suspicions and doubts" and a "growing sense of disharmony" within the relationship (van Wijngaarden et al., p. 7, 2018).

Uncomfortable emotions expressed by the carer such as anger, guilt, uncertainty, and feeling trapped, are discussed in literature as being responses to the changing behaviours of the PWLD and the subsequent increasing demands on carers (Grose, Frost, Richardson, & Skirton, 2013; Sabat, 2010; van Wijngaarden et al., 2018; Walters, Oyebode, and Riley, 2010). Changes in interaction can decrease the intimate feelings experienced by the carer toward the PLWD (Frank, 2008; Hayes, Boylstein and Zimmerman, 2009; Tretteteig, Vatne, & Rokstad, 2017; van Winjingaarden et al., 2018).

A reduced sense of intimacy related to the changing circumstances of dementia is reflected in a loss of self of the carer (Bursch & Butcher, 2012; Furlong & Wuest, 2008; Karner & Bobbitt-Zehler, 2005; Todres & Galvin, 2006). This loss of self is expressed in an excerpt: “I am grieving the loss of self. The person I knew as me is going, fading away. I am doing nothing with my life” (Bursch & Butcher, 2012, p. 212). Loss of intimacy experienced in the relationship results in the loss of self by carers when they question who they are in the relationship. Karner & Bobbitt-Zehler (2005) describe that this loss of self begins a process to regain a sense of mutuality with the PLWD.

The carer role is an attempt “to restructure and protect their relationship to the PLWD in an artful and meaningful manner” (Karner and Bobbitt-Zehler, 2005, p. 563). Ambivalence to taking over the carer role is identified in several studies (Molyneaux et al., 2012; O’Connor, 2007; Purves, 2011). Graham and Bassett (2006) found that when someone takes on the role of carer, the perception of what this means is important to the sense of mutuality with the PLWD. These researchers suggest that a sense of mutuality continues for the carer when they identify their role as caring *about* the PLWD rather than caring *for* the PLWD.

The expression of uncomfortable emotions and the loss of self are significant aspects of the interaction between the carer and PLWD. The emotions and experienced loss of self discussed by the carer in individual interviews are not always expressed in the interaction with the PLWD. One study suggests that the carer may conform to “meet feeling rules about what it meant to be a good caregiver” (Simpson & Acton, 2013, p. 55). Silverman (2013) found how normative responses can sometimes express a dissonance between the publicly expressed emotions and the private emotions. This excerpt illustrates the dissonance of a daughter towards her mother within a video-taped interaction:

It is early morning and Rebecca has just brought Molly to the bathroom and placed her on the toilet. She walks into the kitchen to make a phone call. She holds the telephone to her ear with her right hand. With her left hand, she wipes her forehead slowly and closes her eyes for a few seconds. She opens her eyes, places her left hand on her left hip, purses her lips and gazes straight ahead. She then turns to face the bathroom and calls to Molly in a cheerful voice, “You ok there Mom?” (Silverman, 2013, p. 293)

The excerpt illustrates an interpretive process being used by the daughter to manage her own responses to her mother to fit normative expectations. The daughter’s response suggests her efforts toward mutuality in interaction with her mother.

The efforts toward mutuality are often interpreted as normative expectations of carers in the context of dementia. For example, wives of husbands with dementia are described as protecting their husband’s sense of competency (Beard et al., 2012; Perry & O’Connor, 2002). Perry and O’Connor (2002) decipher this tendency as reflecting “woman’s identity as formed and judged within relationship” (p. 60). Hayes et al. (2009) explained the differences in the responses of wife and husband carers as being related to the social position of the PLWD prior to the onset of dementia. Social norms can result in women carers downplaying their need for support (Eriksson, Sandberg and Hellström, 2012; Silverman, 2013). In a few studies, gender



was related to how the carer expressed their experiences within the interaction. Hayes et al., for example, found that the wives who were carers described themselves less as wives and more as mother figures to their husbands with dementia whereas men less frequently discussed this change of identity. In contrast, Beard et al. found that husbands were more inclined to describe the unhappiness they experienced when dealing with the changes in their wives living with dementia.

In summary, the relational approach considers how the social self of the carer is expressed in the interaction. The subjective expressions of heightened emotions of carers are related to the carers' changing self and perceived roles. The social self of the carer may modify their outward expression of their uncomfortable emotions to meet normative expectations.

### **The PLWD and the Social Self**

The relational approach involves describing how the social self of PLWD responds to the context of dementia. The dependency and loss of individual autonomy of PLWD in our society deems them as not normal, thus PLWD feel stigmatized and feared (McParland et al., 2017; Phinney, 2011). The research identifies that normative expectations collude with the diagnosis of dementia and result in the PLWD experiencing a sense of loss of social self (Clarke et al., 2010; Phinney).

Narratives from PLWD describe how their social self is responding to dementia (Phinney, 2011). This social response is associated with a person's anticipated loss sense of self: "I plan to end my life before I really can't function. I think that not functioning is not living as far as I'm concerned" (Phinney, 2002, p. 261). The significance of having a sense of competency and autonomy in order to be in relationship is also captured by a man living with dementia by his response to having dementia: "Everything I've accomplished in my life I've

worked hard to get, but there's nothing there to work for, and I got it, and it's not that comfortable a feeling" (Phinney, Dahlke & Purves, 2013, p. 357).

In another study the PLWD recognizes how memory impairment is reducing his sense of connection with others:

But I think that's the worst, because it upsets you, you're not one of the boys again, at all you see. Whereas you should be talking to people about the old days and telling them all about it, I can't do it. (Clarke et al., 2010, p. 106)

The PLWD expresses guilt, loss of confidence and a loss of agency in relationship. For instance, in one study, the PLWD describes feeling guilty about the increased demands his dementia puts on his wife (MacRae, 2010). In another study the PLWD describes her loss of confidence exemplified in the following excerpt: "I'm not suggesting I was super-duper, but I could, you know, and now I've lost a lot of confidence because of this problem (Dalby, Sperlinger, & Boddington, 2012, p. 83).

Studies illustrate that the PLWD maintain their social self when their value as a social self is based on positive interdependence with others (Hydén & Orulv, 2009; Phinney, 2011; Rodriguez, 2013; Westius, Andersson, & Kallenberg, 2009). This is illustrated in the following statement made by a man living with dementia: "It's taking something away from me. . . . I'm just losing things out of my life . . . But I'm gaining things too. I see my family struggling to put up with me, and I know that they love me (Phinney, p. 263).

Studies suggest that selfhood of the PLWD is expressed when the interactions foster their sense of who they are in relationship (Kelly, 2010; Sabat, 2002; Sabat & Lee, 2011). Continued selfhood is expressed when the PLWD engages in sharing experiences, choosing the experience of mutual company (selecting a seat close to a person who they enjoyed interacting with), requesting and helping each other, sharing humor and interpersonal understanding, and showing

empathy including helping to save face (Sabat & Lee,). These studies position PLWD behaviour as responses that “reflect their capacity for meaning making” (Sabat & Lee, p. 321).

Continued agency in relationship is found in PLWD meaning-making when telling their stories. The telling of the story can reinforce their sense of who they are in relationship (Hydén & Orulv, 2009; Westius, et al., 2009). Rodriguez (2013) study of the online interaction among persons with mild to moderate dementia found that their interaction facilitated their “reaching back to grasp a piece of the past and bring it forward in temporal space” (p.1224). For persons with more advanced dementia, the telling of the story may rely less on memory and language and more on the encouragement by nursing staff and family members (Hydén, 2013; Hydén & Orulv, 2009). The narrative, in this situation, involves the scaffolding of the story from familiar others (connecting pieces of the story for the PLWD), the use of paralanguage, tone of voice, gestures and dramatized body expression (Hydén, 2013).

PLWD show agency by maintaining roles significant to their sense of social self (Atta-Konadu, Keller, & Daly, 2011; Graham & Bassett, 2006; Hellström, Erikson & Sandberg, 2015; Merrick, Camic, & O’Shaughnessy, 2016). In one study, it was found that women living with dementia maintain their sense of self through their home, through a polarizing division of labour and through re-negotiation (Hellström, Erikson & Sandberg, 2015). In another study, it was identified that conflict would arise if the husband carer did not recognize and support the ongoing role of their wife as the homemakers (Atta-Konadu, Keller, & Daly, 2011). Boyle (2017) identified that men living with dementia showed their agency within interaction by maintaining their working identity. Women with dementia expressed agency in their engagement with helping others and in their religious beliefs and practices (Boyle, 2017).

Like the studies that describe the social self of carer, studies of PLWD suggest that the social self responds to the context of dementia. Studies identify that the social self is lost when PLWD see themselves as a person 'who is dementia' rather than as a 'person first with dementia' (Kelly, 2010; Kitwood, 1997). The social self is maintained when there is positive interdependence with others and when the person expresses their agency within interaction.

### **Personhood and the Interaction between the Carer and the PLWD**

Research using the personhood concept focuses on how the relationship shapes the experience of dementia. Forbat (2003) describes the personhood concept as "radically humanizing" (p. 68) because it recognizes how the interaction and relationship is integral to how the PLWD and their carer experience dementia.

A few studies exemplify the application of Kitwood's (1997) personhood to interaction by analyzing if the carer is bestowing personhood or not bestowing personhood on the PLWD (Adams & Gardiner, 2005; Smebye and Kirkevold, 2013). In the study by Adams and Gardiner (2005), disabling behaviours of the carers diminishes PLWD personhood, while enabling behaviours support their personhood. Disabling behaviours in Adams and Gardiner's (2005) study include: interruption; using technical or complex language; talking out of ear shot; and ridiculing. Disabling behaviours occur when the carer excludes the PLWD by reducing their opportunities to be engaged and exclusion in conversation. Responses of carers that are interpreted as enabling PLWD personhood are: removing distracting or unwanted stimuli; sitting facing the PLWD, or in a position that promotes their equal participation; providing opportunity for them to talk; being sensitive to nonverbal cues; valuing and respecting contribution; and promoting joint decision making (Adams & Gardiner, 2005).

How personhood is bestowed within an interaction between a carer and a PLWD is not always clearly presented in the research. Perry and O'Connor (2002) identified the personhood approach as preserving the "essence of the person" (p. 56). The following exemplifies how a carer supports the personhood of her husband: "I do not allow myself to feel sad because that would not help my husband, because that would not help my husband at all. I don't want him sad...I suppose he knows when I am sad" (Perry & O'Connor, 2002, p. 59). In another study, Beard et al. (2012) identify the essence of the PLWD through the carer's depiction of the PLWD in the interaction: "He does not do as many things around the house. But, he found an error in our statement that the bank had made...He's pretty sharp at that" (Beard et al., p. 4). Similarly, the daughter of a man living with dementia keeps the essence of her father by not correcting her father and thus upsetting him. This excerpt illustrates the dilemma: "If I said, that wasn't quite the correct answer or why you don't you do it like that...I don't want him to get frustrated, like I don't want him to feel bad or not come over to our house" (Phinney, Chaudhury & O'Connor, 2013, p. 361).

Positioning theory has been used to analyze if the carer is bestowing personhood on the PLWD (Shakespeare & Clare, 2005; Purves, 2011). In this theory, interaction is analyzed using conversation analysis. This analytical approach looks at how one person tries to understand the other and is applied to decipher how each person is negotiating their position or role within the interaction (Purves, 2011). Carers who support important roles the PLWD had (or have) equalize them in their relationship and this is interpreted as honoring the personhood of the PLWD (Purves, 2011). Alternatively, carers who decrease any significant role the PLWD has in the interaction or everyday activity diminish their personhood by ignoring the abilities of the PLWD (Chatwin, 2014).

Studies discussed so far have applied the personhood concept recognizing how the carer can shape the experience of dementia for the PLWD. It simplifies the dementia experience by dichotomizing the responses of carers as either bestowing PLWD personhood or not bestowing their personhood (Adams & Gardiner, 2006; Smebye, & Kirkevold, 2013). Simplifying an understanding of the interaction and dichotomizing relationship is critiqued in recent literature (McParland, Kelly, & Innes, 2017; Tolhurst, et al., 2017). By considering only the carer's influence on the PLWD, the social structures in place that contribute to disability of the PLWD and lead to the carer expressing disabling behaviour are not acknowledged (Bartlett & O'Connor, 2007; McParland et al.).

As it is applied, the personhood concept puts all the responsibility on the carer in the interaction. The concept of personhood does not consider the dementia context as shaped by the societal medicalization of dementia. Further, it does not recognize the agency of the PLWD. The concept of personhood "positions the person with dementia as passively dependent" (Bartlett & O'Connor, 2007, p. 110) because personhood is *bestowed* on them. Application of personhood can diminish an understanding of the bidirectional nature of interaction that would shape a mutual dyad experience of personhood (Bartlett & O'Connor, 2007). Molyneaux et al. (2012) look at the interactions of the intimate couple and identify how a mutual lack of personhood reverberated with both the spouse and the PLWD.

Forbat (2003) applies a socially contextualized understanding of personhood to a discourse analysis of a mother and daughter's individual description of their relationship. The personhood of the PLWD is not recognized by the daughter because the daughter sees herself as a victim of her mother's difficulty. The daughter does not bestow personhood on her mother based on past difficult relational interactions with her mother. In a recent study, Tolhurst et al.

(2017) broaden an understanding of personhood to include those “constructions and attributions involved in the maintenance of the interpersonal relationship” (p. 231). Tolhurst et al.’s application of this broadened understanding of personhood addresses a concern about the lack of balanced perspective in applying the personhood concept with the relational approach.

The relational approach in studies exploring the intimate couple is challenged to analyze the complexity of interactions so as not to perpetuate the negative stereotypes of dementia or minimize the challenges encountered by the intimate couple (Tolhurst et al., 2017). This literature review further explores the relational approach of research by considering how research has described the interaction of the intimate couple.

### **Descriptions of the Dynamics of Couples’ Interactions**

Researchers employing a relational approach examine the interaction of the intimate couples. The dynamics of the couples’ interactions depict how spouses take each other into account in their interactions and how they proceed in their everyday activity in the context of dementia. The research exploring intimate couples has some gaps that limit the insights into how the context of dementia shapes intimate couples’ life together. Though a few studies provide valuable insights into how the intimate couple adjusts and lives within the context of dementia, there is a dearth of current research describing the intimate couple. There is no current model that can guide a balanced understanding of what is happening between the partners of the intimate couple in their journey with dementia.

### **Different methods used to explore the relationship of the intimate couple**

Different methods have been applied to understand how the interaction reflects the adjustments of the intimate couple to their context of dementia. The joint interview is described as an opportunity to gain the best insight into how the intimate couple make adjustments in the

interaction and therefore how they are managing their life together. There is some difficulty with this because studies exploring the interaction of the intimate couple are limited because the PLWD is often in the earlier stages of dementia. However, the variety of approaches used to understand the interaction of the couple builds the knowledge of understanding about the intimate couple.

Joint interviews have not been used to study the intimate couple because of ethical concerns that joint interaction could stimulate discussion on difficult subjects and leave the couple feeling unresolved (Eisikovits & Koren, 2010; Voltelen, Konradsen, Östergaard, 2018). There is also concern that one of the spouses might be inhibited to speak freely or that one spouse may dominate the interaction (Valentine, 1999; Zahrin, 2018). However, understanding the interactive environment can provide insight into how the couples are adjusting to their context of dementia. Studies that use joint interview with the intimate couple suggest that this provides the best insight into how the couple interacts and provides a unique understanding of how joint stories are produced (Eisikovits & Koren; Polak & Green, 2015). Using the joint interview has also been seen as problematic for the intimate couple because of the changes in the linguistic ability of the PLWD in later stages (Molyneaux et al, 2012). This may be the reason that, for most qualitative studies exploring the relationship of the intimate couple, the PLWD is in the early stage of the dementia journey (Beard et al., 2012; Keady & Nolan, 2003; Nilsson, 2017, Tolhurst et al., 2017). PLWD further along the journey with dementia demonstrate ongoing intersubjectivity with their spouse (Boyle & Warren, 2017) suggesting the possibility of learning from intimate couples about their adjustments in these later stages of dementia. Different approaches have been used as a basis for interpreting the joint interview and contribute to the understanding of the intimate couple living with dementia.



The narrative approach describes how each partner of the couple makes sense of their experience by comparing their past experience with their current experience in dementia (Davies, 2011). Researchers describe using thematic analysis to understand the interactive features of the interaction (Fletcher, 2018; Tolhurst et al., 2017). Researchers applying grounded theory describe using constant-comparative analysis (Beard et al., 2012; Hellström et al., 2007; Molyneaux et al., 2012). Conversational analysis has been used to sort out how the symptoms of dementia impact the interaction (Nilsson, 2017) and to discern how the intimate couples position each other in the interaction (Clare & Shakespeare, 2004). Missing is a usable approach that can be applied across the stages of dementia to distinguish features of the conversation and a narrative that can guide how the interactions of the intimate couple are responding to their context of dementia.

### **Adjustments in the Interaction**

Findings from studies exploring the intimate couple do provide insight into how couples are making adjustments in their interactions as they live with their context of dementia. Studies describe that as couples adjust to each other and to their context of dementia, they co-construct their relationship and their life together.

Keady and Nolan (2003) were the first to describe how the context of dementia was shaping the dynamics of the couple. Keady and Nolan applied the term of ‘working’ to capture how each person was putting effort into understanding the other in interaction and how this effort changed their responses and interactional dynamics. The phases of the interactional dynamics that Keady and Nolan refer to are: working alone, working together, and working separately. A fourth, less-common phase is working apart and occurs in circumstances in which couples cannot reach the phase of working together because of past relational difficulties. In this research, the

context of dementia shapes the interaction because the working done by each couple is related to their recognition of the diagnosis and symptoms of dementia. Other researchers have applied Keady and Nolan's working phases to different aspects of the intimate couple's dementia journey (Beard et al., 2012; Hellström et al., 2007; Hellström, Lundh, & Nolan, 2005).

The phases of 'working' demonstrate how the relationship is shaping the experience of dementia for the couple. The first phase, called working alone describes the carer concealing the extra work they are doing because of the symptoms of dementia of the PLWD and the PLWD trying to conceal their dementia. The carer does not want to embarrass the PLWD. In their phase model, Keady and Nolan (2003) describe that working together occurs when each person in the relationship begins to talk about their awareness of the circumstances and they seek solutions together. This excerpt is said to illustrate the couple working together: "I know I have Alzheimer's disease, but what can anyone do about it? I do silly things now but we just try and laugh about it. We have a saying, "pick up the pieces and start again" (Hellström et al., 2007, p. 29). Hellström, Lundh, and Nolan (2005) identified the working together phase as a phase in which the abilities of the PLWD were supported by the carer.

The phase model described by Keady and Nolan (2003) identifies how efforts toward mutuality change and how the carer and PLWD are accommodating for each other. Concerns in the application of the phases are their lack of conceptual clarity. How can the activity of working alone, separately or apart be distinguished within the interaction? The phases acknowledge the struggles the intimate couple can have within the context of dementia, but the description of the phases does not account for the variation in the way couples make efforts toward mutuality (Beard et al., 2012, p. 8). Beard et al. state that describing the specific phase is

less important than noting the work that is going on within the intimate couple toward shared understanding.

Studies support that the intimate couple co-construct their relationship (Graham & Bassett, 2006; Hellström et al., 2007). Graham & Bassett interviewed 86 dyads (joint and individual interviews conducted several times over a year) to understand the give and take in the relationship between the PLWD and their carer. Their findings identify the complex interplay between disease progression, everyday activity, social environment and relational history. In their study, researchers describe how some carers continued to perceive reciprocity in their relationship with the PLWD. Findings also discuss how some PLWD recognized the difficulties carers were having living with the changes that were occurring related to the dementia. Graham and Bassett provide individual excerpts from the PLWD and their family but do not analyze what is happening in the interaction. They identify an array of influences on the couple and the interaction but do not provide a consistent description of the interaction of the couple. They do provide the picture of the relationship between the PLWD and their carer as “rich and ambiguous” (p.335). Graham and Bassett’s findings are that couples are co-constructing the caring that occurs in their relationship.

Hellström et al. (2007) provide a clearer guide for understanding what is happening in the interaction within the intimate couple as they co-construct their couplehood. Hellström et al. studied 20 different couples over the course of five years. Different phases of the couple interactions relate to where they are in their dementia journey. These different phases are: sustaining couplehood, maintaining involvement and moving on. In these relationships interactions within the intimate couple foster their reciprocity and their long-term relationship. Couplehood includes interactions that recognize the equal contribution of the PLWD (Beard et

al., 2012; Merrick et al., 2016; Molyneaux et al., 2012). The earliest phase of the intimate couple's journey is sustaining couplehood. The types of interactions associated with this phase are couples talking things through, affectionate talk and being appreciative toward each other. Other researchers applying the sustaining concept identify that in this phase the intimate couple "minimize the impact of the disease" (Molyneaux et al., p. 489). The maintaining involvement phase suggests that the carer increasingly needs to take initiative on previously shared activities. Role changes occur in the maintaining phase, for example, as husband carers become more involved in housekeeping chores. Maintaining also meant that PLWD realize that they can no longer do the things they used to do and become more accepting of the assistance they require. Hellström et al. describe the 'moving on' phase as a decrease in mutuality between the carer and the PLWD. Some carers continue their relationship with their spouses by being involved with the long-term care facility where the PLWD has relocated. Mutuality, however, is described as no longer apparent between the PLWD and the carer. Hellström et al. describe the PLWD as becoming passive and uninterested in engagement.

The interactions of the intimate couples in these different phases depict a linear process following the changes (associated with dementia) in the PLWD. The interactional changes are related to PLWD diminishing abilities to participate in everyday activity and subsequently increase the responsibility of the spouse. The interactional dynamics illustrating the changes that occur within the couple are not discussed or incorporated in the phase model. Of added concern is that the different phases are associated with reduced abilities of the PLWD. These reduced abilities culminate in the final phase suggesting a complete lack of couplehood. The linear description of how couples preserve couplehood through their journey presents a positive picture at the beginning of the journey and a negative picture at the end. The phases do not

acknowledge the ongoing abilities of the PLWD nor do they recognize any real potential for the couple's mutuality between the couple near the end of their journey.

Recent studies exploring the intimate couple also apply the concept of couplehood (Beard et al., 2012; Molyneaux et al., 2012; Merrick et al., 2016; Sinclair et al., 2018). Findings from these studies confirm that couplehood is maintained within the interaction through negotiating roles, through the process of PLWD reconstruction of self, and through normalizing the experience (Beard et al.; Molyneaux et al.; Merrick et al.). Findings provide insight into how couplehood is negotiated and co-constructed.

Negotiation described in some studies suggest a back and forth in the interaction to sort out the meaning of the disability and the meaning of changing roles to the intimate couple (Beard et al. 2012; Fletcher, 2018; Molyneaux et al., 2012). The concept of joint career has been applied to understand how the couples interact in their context of dementia. The joint career presents the intimate couples' joint interactions as "socially constructed and negotiated" (Beard et al., 2012, p. 3). Fletcher describes the joint career as a process of "interpretive interpersonal interaction" (p. 8) that occurs within the couple as they adjust to the experience of dementia. In the joint career, the relationship shapes the context of dementia as couples negotiate and subsequently adjust to changing roles (Beard et al.; Fletcher). Fletcher suggests that being in a long-term relationship can make the experience of dementia more troubling because of well established role expectations that need to be renegotiated by the couple.

The process of adjustment can involve conflict according to Fletcher (2018). Beard et al. (2012) describe how intimate couples negotiate memory changes in everyday activities. Further, Beard et al.'s study describes the couple as managing the disability and supporting the autonomy of the PLWD. An aspect of the negotiating by the couple is to minimize the impact of dementia

in their life. This is exemplified in interactions in which the intimate couple describes the changes related to dementia as age-related. Fletcher presents the interactions when the PLWD is in later stages of dementia. These interactions focus primarily on the response of the carer to the increasing demands of the context of dementia rather than a description of the interaction that occurs in the intimate couple.

Research that describes how couples co-construct their relationship or how they have a joint career does not describe the details of the interaction occurring in the joint interview to discern its meaning for the relationship. Nilsson (2017) applied conversational analysis to explore how intimate couples (PLWD in early stages of dementia) respond to each other when telling a story about themselves. Nilsson found carers adapt the amount of information that they contribute to the interaction and often provide cues to the PLWD. The metaphor of fishing was used to describe the strategies used by the carer to facilitate the memory of the PLWD and her ability to contribute to a well known story. A video of the PLWD demonstrates how the PLWD expressed embarrassment in response to the carer's strategies and the researchers question whether the fishing done by the carer is always helpful for the PLWD. They speculate that the PLWD experiences distress because they recognize that they do not know something they should know.

Tolhurst et al., (2017) also looked at the details of a joint interview of an intimate couple to discern how broader social influences are being expressed and managed within the interaction of the intimate couple. In the case study presented, the husband (PLWD) presents a positive picture of their current context of dementia exemplified in their statement: "I just feel a lot more in charge of myself, with working and doing things" (Tolhurst et al., 2017, p. 220). This is in opposition to the wife carer's experience of dementia as she immediately responds to her

husband's comments "But I think for me, it gave me all the responsibility" (Tolhurst et al., 2017, p. 220). The carer presents a more negative view of their context of dementia. It is noted that the wife shows awareness of her husband's need for independence and autonomy. The carer later makes efforts toward mutuality by stating she too has difficulty with losing things. The husband resists any implied difficulty he is having by using humour. The wife, on the other hand, seems to need to provide an account for the degree of frustration and hardship experienced in the context of dementia. Tolhurst et al., (2017) identify that within the interaction each person has different "face saving and normalizing accounts" (p. 221) that reduce the PLWD sense of declining ability. The significance of how each person narrates their self-identity is a response to the social expectations of independence and self-sufficiency. It is suggested that differences in the narrative prerogative of each person resulting from dementia causes "intense biographical disruption" (Tolhurst et al., 2017, p. 222). These findings are similar to those of Shakespeare and Clare (2005). In their study, couples' interactions are recorded when they are left alone for five minutes. They are asked to describe how life has been changed by dementia. It was found that the PLWD often asserted their rights and the spouse would modify their negative comments to facilitate the self-identity of the PLWD.

The research describing how a couple's interaction is influenced by the context of dementia provides insight into how the couple adjusts to each other and to their circumstances of dementia.

### **Summary of Chapter 2**

I reviewed literature that was guided by the relational approach. In the first section I discussed the social self of the carer and the social self of the PLWD. The social self of the carer is often described as having emotional difficulty in the context of dementia (Hayes et al., 2009;

Silver, 2013; Walters et al, 2010). The emotional difficulties are associated with the losses they experience and the loss of the social self (Karner & Bobbitt-Zeher, 2005). Normative pressures including gender related expectations are described as influencing how the carer interacts with the PLWD.

The PLWD social self is at risk related to neurological changes and the attitudes of others towards them (Sabat, 2002). Studies exploring the experience of the PLWD suggest that the PLWD social self is maintained in situations in which they experience positive interdependence (MacRae 2010; 2011; Phinney, 2011). Research also describes the potential agency of the PLWD as contributing to their continued social self. This agency is revealed in how the PLWD can respond with empathy in interaction and how they can insist on maintaining certain roles in their everyday activity (Boyle & Warren, 2017).

The second section of my review described how the personhood concept has been used to understand the interaction of the intimate couple. Research applying personhood explored specific responses of the carer toward the PLWD. This approach to understand the interaction of the intimate couple does not consider how the context of dementia might be influencing the personhood of the carer (Davis, 2004). Other studies show how the carer promotes the personhood of the PLWD by reinforcing their previous and current roles in their relationship (Purves, 2011). The concept of personhood can provide insight into the interaction of the intimate couple, however, its application needs to be broadened to consider how both relational history and the impact of medicalization on the carer influence the expression of personhood in the interaction (Forbat, 2003; Tolhurst et al., 2017).

The third section of this review presented studies that described the adjustment of the intimate couple in the interaction. The method of using the joint interview was discussed as



providing the best opportunity to understand how the couples are interacting. Different approaches used to understand the joint interview have led to significant insights about how the couples adjust to each other in the context of dementia.

Research that exclusively studies spousal relationships identified how couples' co-construct their identity as an aspect of their everyday interactions (Daniels, Lamson, & Hodgson, 2007; Davies, 2011; Hellström et al., 2007; Merrick et al., 2016; Molyneux et al., 2012). Interactional dynamics are described as couples working to understand each other and to accommodate for how the other might be experiencing their situation. Studies describe how the couple's interactions co-construct their couplehood. Couplehood represents the couple's behaviour that fosters their ongoing relationship. Studies also describe how couples negotiate their joint career, that is, how they make ongoing adjustments to cope and live together. A few studies look at how each spouse is accommodating for the other. These studies provide further insight into the dynamics of the interaction and how the intimate couple adjusts in the context of dementia.

### **Chapter 3: Methods**

This chapter describes the methods used to explore the efforts toward mutuality of the intimate couple. First, I reintroduce the research questions. Second, I describe the ethnographic methods I applied to this study. Third, I analyze the data and provide examples of the analytic process. Fourth, I describe the rigor in the methodological process applied to the research design of this study.

#### **Research Questions**

1. How do intimate couples within the context of dementia respond to each other:
  - a) While discussing everyday activities and describing their relational story and
  - b) While interaction during routine activities and novel activities?
2. How do the responses of the intimate couple shape their mutuality as a couple within the context of dementia?

#### **Focused Ethnographic Methods**

I applied focused ethnographic methods to explore how intimate couples living within the context of dementia make efforts toward mutuality. Focused ethnographic methods are applied to learn about how people are responding to current social situations (Knoblauch, 2005). Prus (1996) also emphasized that social ethnographic approaches facilitate accessing those interactive processes of people's lives that allow them to form their life together. The outcome of focused ethnographic studies often illuminates concepts that help health care providers' better understand how people respond to health related issues (Cruz & Higginbottom, 2013).

Focused ethnographic method aims to understand what is happening at the micro-level interaction to shed light on the macro-social environments that is assumed to influence the interaction. In applying focused ethnographic methods, Knoblauch identified that the researcher investigates people's way of life through their "communicative activities" (Knoblauch,p.2). In

my study, the current social situation is the context of dementia. The micro-level understanding occurs by attending to communicative activities or how they are making efforts toward mutuality. At the micro-level, each couple integrates the macro-level implications of having dementia including what the symptoms mean within the complexity of their own relationship and social situation. Understanding the intimate couples' efforts toward mutuality facilitates health care providers' understanding how the broad social implications of the diagnosis are intertwined with the understanding of the neurological implications of dementia.

Focused ethnographic procedures were implemented in my study to gain an understanding of this micro-level experience of the couple. These procedures include a narrow scope of inquiry, intense intermittent periods of field work, audio recording, field notes and transcripts and short amounts of time to collect the data and intense data analysis (De Chesnay, 2015; Knoblauch, 2005).

Applying focused ethnographic methods utilizes the principles of ethnography to attain knowledge that would not be easily gained through other methods (Savage, 2000). Gaining the emic perspective by using the researcher as an instrument, puts the researcher in close proximity with their participants, and can potentially access "dimensions of the social world that are covert and tacit" (Cruz & Higginbottom, 2013, p.42). Focused ethnographic methods, like other qualitative methods, must take into account the researcher and the researcher's strategic account in the findings (Salvage). Knoblauch (2005) identifies that focused ethnography is based on an understanding that the researcher has knowledge of the field they are studying.

Focused ethnographic method facilitates data collection procedures that apply participant observation to acquire a broad and in-depth understanding of each intimate couple's efforts toward mutuality within the context of dementia (Cruz & Higginbottom, 2013; De Chesnay,

2015). Participant-observation and interviews are the data collection method used to gain an understanding of the participants' perspectives on the phenomena under study or their emic perspective. Participant-observation is a strategy which facilitates acquiring an emic perspective because the researcher engages in the participants' life in their natural setting (Creswell, 2013; Cruz & Higginbottom, 2013). Participant-observation positions the researcher to understanding the participants' perspectives by engaging in the joint communicative process with the researcher. This facilitates trust between participants and the researcher and leads to attaining quality data (De Chesnay, 2015; Guendouzi & Müller, 2006). Formal and informal interviews are important techniques used by ethnographers' to collect data that is analyzed (Cruz & Higginbottom, 2013). The data collection methods involve participant-observation took place in the naturalistic setting of the couple's home.

**Participant-observer positions.** There are four different positions of participant-observer described by Roper and Shapira (2000). The positions vary in the extent to which the researcher attempts to fit into the dynamics of the interaction (Prus, 1996). On the extreme of the continuum, the participants in the study are not aware that the researcher is present as an observer. On the other extreme the researcher is being a full participant. In my study, couples were aware of my position as a researcher at all times and my positions included a fluid movement between the observer as a participant and participant as an observer. This facilitated a trust relationship with the intimate couple and encouraged their interaction within the joint interview (Bogdan & Taylor, 1975; De Chesnay, 2015).

Though I moved in and out of different positions of the participant-observer, I was aware that in certain research activities, one of the positions was dominant. In an observer as participant position, the researcher tries to remain "unobtrusive or nondisruptive" (Prus, 1996, p. 20). In the

participant as observer position, I was more engaged in the dynamics of the interaction occurring between the couple. The participant as observer position was most prominent when I engaged in routine everyday activities with the couple; the observer as participant was most prominent when the couple was making a selection of photographs and when I noted the environment of the couple, or the behaviours occurring within the interaction during interviews.

***Reflexivity of the researcher.*** Reflexivity of the researcher occurs throughout the research process to provide as much transparency as possible on the researcher's influence in the findings (Olson, 2011). I included my reflections of the field experience in my post interview guide (Appendix 9). I reviewed and reflected on how my own experiences, values, bias and expectations might be influencing my participation and therefore the couples' interactions. My previous experience as a nurse provided me with a comfort level in working with couples who were experiencing changes in the context of dementia. In the process of acquiring and interpreting data, my clinical experiences shaped my expectations in the field and the participant-observer positions. The relationship I had with the couples meant that at times I provided health care resource information. The societal role of the nurse is to support clients and provide health care information. When couples placed me in the nurse clinician role, I would offer practical information.

As a researcher, my roles were as data collector and interpreter. The role of the researcher is to encourage participants' talk about what they know of their world. I found that I often brought my own personal experiences into the couples' conversations. This included relating to the pictures, ornaments and musical instruments that were in the couples' homes. One intimate couple, for example, had a picture of themselves kayaking. I expressed my own interest

in the activity and asked them to tell me about where and when they kayaked. The natural setting of the couple's home facilitated discussions about their life together.

My experiences of interacting with the couples were described in the post interview guide and included my reflections of the expected and unexpected. At times I experienced discomfort when misunderstandings within the couple were expressed and I struggled with maintaining the observer as participant role. However, there may have been times when I was too quick to redirect or avoid topics that might to escalate the misunderstandings of the couple. A few of the couples indicated that they felt listened to and gained some insight about their situation in telling their story for the purpose of the research. As a researcher, I offered the couple the opportunity to tell their story and I offered them gratitude, a thank you card and a photo-album of the photographs I took. For those couples who did not have photographs as an aspect of the research process, I gave them a card and flowers at their final interview.

### **Accessing the Field**

The naturalistic setting of the couples' homes provided the back drop to applying methods of participant observation to facilitate how each couple made efforts toward mutuality. This section describes the ethical and methodological procedures and considerations that were addressed to access the field prior to data collection. These procedures are described and include: obtaining ethical approval, the inclusion criteria, sample size and recruitment of participants.

**Ethical approval.** Ethical approval was sought and granted by the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba (approval in Appendix 1) prior to engaging in recruitment for my study.

**Inclusion criteria.** The inclusion criteria included couples who were in an intimate relationship (the intimate couple) living in the community. To meet the inclusion criteria, of the study, one of the partners in the relationship had a medical diagnosis of dementia, the PLWD and one did not have dementia (the spouse). The type and stage of dementia were not an inclusion criteria of this study because attention was on the way each couple made efforts toward mutuality within the context of dementia. Inclusion criteria also required that the couple live in the community either living together or apart.

**Participants/Couples.** I used purposive sampling techniques. Learning about the phenomena of efforts toward mutuality of the intimate couple involved spending time with people who live in these circumstances.

The recruitment of nine couples was consistent with the recommendations made by Morse (2000). Morse indicates that sample size considers the amount of data collected through observations and interviews to capture the phenomena of interest. In my study, the number of couples and the visits conducted led to acquiring sufficient data on efforts toward mutuality for each couple. The duration of engagement with each couple was sufficient to acquire saturation in the way they related and made efforts toward mutuality. Of the nine couples, eight were husband and wife couples. On discussion with my advisor it was decided that the daughter and mother dyad represented a distinct group outside the more homogenous group of the eight married couple. I decided not to include the data collected with the daughter and mother dyad in my analysis.

**Recruitment.** I developed posters and leaflets (see Appendix 2) and posted them in local churches and assisted living facilities. The original posters asked the couples to engage in several research activities, including five different field visits. After two months with no expressed

interest, I began the process of inquiring about accessing persons who were known to the Alzheimer Society of Manitoba (ASM). I implemented suggestions by ASM staff to decrease the number of research activities asked of participants. Recruitment procedures changed to request couples participate in one interview. The new poster indicated couples could participate in other interviews but were not obligated to do so. The letter I developed and sent to the ASM is in Appendix 3. This revision in recruitment was approved by ENREB.

The ASM provided significant support in recruiting couples for the study. I was invited to talk about my study to two support groups of PLWD and their spouses. I was invited by the ASM to an education session on end-of-life decision making held at an assisted living complex. I used a script to talk about my study with the couples (Appendix 4). The ASM also advertised my study in the Alzheimer Society Newsletter. All of these activities resulted in the recruitment of seven couples. Two additional couples were recruited through snowballing; that is, a few friends of mine gave couples they knew a copy of the leaflet and the couples contacted me to discuss their potential participation.

In all instances, it was the spouse of the PLWD who contacted me. I provided information to the spouse about the study by following a script (Appendix 5). If the spouse who contacted me met the inclusion criteria and was interested, an initial meeting was set up to discuss the study and commence engagement in data collection if the couples consented.

### **Field Visits**

The intimate couples' homes were the locations of field visits. Achieving voluntary informed consent of couples meant discussing with the couples my ethical procedures and data collection expectations.



**Ethical procedures in the field.** Joint interviews are associated with having ethical strengths and some ethical concerns (Voltelen et al., 2018; Zahrin, 2018). Joint interviews facilitate the rights of PLWD because of the presence of the family members closest to them. Ideally, the spouses can act in full awareness of the research study and the implications for PLWD participation. An ethical concerns identified in recent studies of joint interviews identifies that the interviews may bring up hurtful or difficult matters for the couple. These concerns are addressed in an extended or ongoing consent process and in interview procedures that put the couple's well-being as a paramount consideration.

There were three different consents for the data collection in which the couple could choose to engage (Appendix 6). One consent applied to the first joint interview; the second consent related to the photographing and photo-elicitation with the couple; and the third consent applied to the individual interviews. Consents were signed by both individuals of the couple except for three (Martin and Josephine, Peter and Ruth, Emmanuel and Karen) in which the spouse (wife in all cases) had legal power of attorney and signed on behalf of her husband. For couples in which the spouse signed the consent for the PLWD, the spouse asked the PLWD if this was okay if they (the spouses) signed the consent on their (PLWD) behalf. There was no indication in the interaction that the spouse's signing the consent on behalf of the PLWD affected the rest of the field visit. Verbal agreement was sought from all participants throughout the interview process to ensure ongoing consent. If there was hesitancy or discomfort I reminded participants that they did not have to answer any questions. At the beginning of the first meeting (semi-structured joint interviews) with the couple I let them know that I would be asking them at the end of the interview if they were interested in participating further in the study. I stressed, however, that their engagement in this first field visit was appreciated and that they were under

no obligation to continue with the research. Six couples agreed to be photographed, three of them agreed that I could use their photographs in research presentations. Once consents were signed, data collection began.

An ethical concern associated with joint interviews is that bringing up difficult matters between the couple could potentially lead to couple disenfranchisement once the interview is over (Voltelen et al., 2018; Zahrin, 2018). In conducting these interviews, I was aware that I could ask questions that might spur differences in shared understanding between the couple or that discussion of past stories could result in the recollection of difficult memories for the couple. As is suggested by recent literature, I remained neutral during the joint interview (Voltelen et al.; Zahrin). Over the course of the interview, I paid close attention to those aspects of the couples' interactions that indicated how they reinforced their bond together. In closing the interview, I reviewed those aspects of the couples' lives that solidified their experience as a couple.

**Equipment.** All field visits activities (interviews and conversations) were digitally audio-recorded. A camera was used in photographing the couples who gave permission. Digital photographs were uploaded immediately after the interview and held in a password-protected computer, and were immediately deleted from the memory card after upload. The same procedure was used for securing audio-recordings. There were two devices used to audio-record in case there were problems with one device. Both records of the interview were uploaded immediately after the interview and deleted from the devices. Digital recordings were transcribed verbatim by a transcriber who had signed a privacy oath. Pseudonyms were given to the couples.

**Field visits and research activities.** I conducted 3-5 different field visits with the intimate couples. The number of field visits depended on the extent of their agreement to engage in the research activities and on my discernment of the need for field visits (see Appendix 7, field

visits with intimate couples). Data was collected using joint semi-structured interviews and joint guided interviews. These interviews took place during routine and novel activities. The routine activity involved the couple having coffee/tea and a snack with the researcher and the ‘novel activities’ were being photographed as a couple while engaging in routine activities, talking to each other about the photographs that the researcher had taken and selecting the best photographs together. Semi-structured separate or individual interviews with each partner of the couple were also included in the data collection.

*Semi-structured joint interview of everyday activity.* Polak and Green (2015) suggested that a joint interview provides an opportunity for collecting data that elicits the interactional process of the couple. All couples participated in the first joint interview and discussed their everyday activities. In my study, the first joint interview included data collection. The demographic data is presented in tables 1 and 2.

**Table 1: Demographic Information on the Couple**

<b>Intimate Couples (pseudonyms)</b>	<b>Age of PLWD</b>	<b>Age of Spouse</b>	<b>Length of Marriage</b>	<b>Living arrangements</b>
Martin and Josephine	91	76	41	Martin lives in supportive housing for 6 months and Josephine in their marital home (over 20 years)
Tom and Mary	83	78	57	Together: Home for over 20 years
Harold and Alice	80	78	21	Together: Condominium for 10 years
Paul and Elizabeth	75	72	52	Together: Home for 3 years
Peter and Ruth	82	76	59	Together: Home for over 40 years
Evelyn and John	85	83	50	Together: Assisted Living for 10 years
Emmanuel and Karen	79	72	45	Together: Condominium for 12 years
Sam and Roberta	74	70	49	Together: Home for over 30 years

**Table 2: PLWD: The Diagnosis of Dementia and Functional Changes**

<b>PLWD</b>	<b>How is a medical diagnosis of dementia talked about?</b>	<b>Length of time since diagnosis</b>	<b>Changes in *IADLs</b>	<b>Changes in **ADLs</b>
Martin	Avoided mentioning dementia	TIA's about two years ago	Dependent	None discussed
Tom	Vascular type dementia	One year	Independent	Independent
Harold	Vascular dementia Lewy Body	LewyBody - 3 years ago Vascular -11 years ago	Dependent -can make his own appointments	Uses walker in home and wheelchair for long distances
Paul	Alzheimer's type	3.5 years	Dependent	Independent
Peter	Not discussed	Unclear	Dependent	Dependent in dressing
Evelyn	Alzheimer's type dementia	two years	Increasing dependency	Independent
Emmanuel	Mixed Vascular and Possible Alzheimer's type	3 years	Dependent	Independent eating and mobility only
Sam	Alzheimer's type	4 years	Independent	Independent

\*IADLs – Instrumental activities of daily living

\*\* ADLs- Activities of daily living

In the first field visits with the couples, in-depth, semi-structured, face-to-face, joint interviews were conducted. Collecting demographic data during the joint interview proved to be an avenue for the spouse or the PLWD to elaborate on their past and present circumstances. At times during the interview, interactions occurred between the couple that manifested different aspects of their mutuality.

During the first interview, the couples were asked to describe their everyday activities and how the activities had changed or stayed the same (see Appendix 8 for interview guide). Couples often talked about recent or past activities in which both of them were involved. A grand tour question was posed to the couple: “How have your everyday activities changed in the last few years?” For this initial question, the conversation followed from what the couple chose

to talk about. I as needed intervened to clarify their comments. The probes inquired about specific events and everyday activities that were enjoyable and meaningful to them as individuals and as a couple, such as going out with friends. Probing also entailed asking the couple about other activities related to everyday life including for example, changes in transportation, paying bills, making meals, doing groceries, or mowing the lawn in summer. The first interview also included asking them to describe relational stories, if time permitted.

Joint interviews are associated with methodological strengths and potential weaknesses (Voltelen, et al., 2018; Zarhin, 2018). Though the method of joint interviews has the potential for increasing the depth of the data it can also lead to shallow data collection (Voltelen et al.). Zahrin identifies that data collection can be limited by couple desirability or the interest of each partner to please the other in the interaction. In my study, focused ethnographic methods acquired information about the couples' everyday activity and interaction because the researcher was the instrument. Using different positions as a researcher facilitated acquiring depth in understanding the couples' efforts toward mutuality.

***Guided Interviews.*** 'Guiding interviews' (Olson, 2014) are meant to encourage the couples' telling of their stories. The guiding interview has a few broad questions meant to encourage the participants to talk. Olson indicates that the guiding interview has more structure than an unstructured interview but is less constrained than a structured or semi-structured interview. In being less constrained, the participant may talk about something that would not otherwise be captured about the phenomenon of interest. In my study, guided interviews occurred during routine activities and novel activities.

During routine activities, I asked the couple to tell me a relational story. A routine activity in which the couple and the researcher engaged was having coffee or tea and a snack

during the interview. There was one visit in which the spouse prepared and served lunch. The novel activities in which the couple could choose to participate or not participate was being photographed, selecting photographs (photo-selection) and discussing photographs (photo-elicitation). When being photographed the couple was asked to continue to engage in their routine activity and to continue to discuss their relational stories. Hesse-Biber and Leavy (2011) state that since photography is a form of interactive research, it shapes the social reality expressed in of the interaction. Six out of eight couples participated in the activity of being photographed, and photo-selecting with photo-elicitation. Photographing took place while the couple engaged in their routine everyday activity of having coffee. Couples often selected to pose for photographs. The couples were encouraged to continue talking, but the camera often captured their attention and took away from the interaction I wanted to capture. Encouraging relational stories could included asking the couples to tell stories about the objects (such as a piano) and artwork they had in their home. I asked permission to photograph inanimate objects such as pictures on the walls, ornaments and piano. I used these photographs to trigger discussion during photo-elicitation.

Once the photographs were developed, I returned for another field visit in the couples' homes and asked them to describe what was happening in the photographs and to select the photographs they liked the best. Initially, I had planned two separate visits with each couple once the photographs were developed. The first of these two visits would involve photo-elicitation; however, I found the interest of the couple was on the quality of the photograph and not in the content. The decision-making process of selecting the photographs for the photo-album was the impetus for most of the discussion about the photographs, that is "which was the best picture?" There was less discussion on the content as it related to the everyday activity than I had

anticipated. The couples' comments about the photos during photo-selection and photo-elicitation were much the same. Therefore, towards the end of the data collection process I planned only one visit in which the couple both selected the best photographs and were encouraged to discuss the activities that were occurring at the time of the photograph. In the photo-selection process the couple selected 10-12 photographs to go in an album. The couples kept their photo album as my gift of appreciation.

*Individual interviews.* Individual interviews with each spouse were conducted with seven of the eight couples. This entailed private face-to-face interviews while the other spouse was not in the room or within hearing distance.

The individual interviews provided an opportunity for a husband or a wife to express something they may not have been comfortable sharing in the joint interview together. However, the review of the individual interviews compared closely to the joint interviews with similar expressions of efforts toward mutuality. Spouses' statements in the individual interview expressed an extension of the circumstances that were occurring in the joint interviews but were sometimes more explicit. For example, in the individual interview Elizabeth (spouse), stated that Paul (PLWD), her husband, is now a "shadow of a puppy" compared to who he had been. Ruth (spouse) provided a few more examples of Peter's (PLWD) difficulties in accepting homecare or any other presence other than hers. PLWD responses in the individual interviews similarly reflected how they expressed their mutuality in the joint interview. For example, Evelyn freely spoke about how her husband had been a difficult person (she also spoke of this in the joint interview). In the individual interviews, both Peter and Paul expressed worry about the absence and location of their spouse. Neither Peter nor Paul could be reassured or easily redirected by me. I did not conduct individual interviews with Emmanuel and Karen because early in the field

visits Emmanuel had been accepted to live in a personal care home, and I did not want to add to their stressors. Though the individual interviews provided saturation of the way each couple expressed their mutuality, they did not contribute a new or different understanding of the couple.

In appendix 7, I describe each visit, the activity that occurred during the visit, the amount of time taken for the visit, and the amount of time between visits for each couple. All of visits took place between February, 2016 and July, 2016. The timing between visits was generally related to the couple's preference and couple's travelling or experiencing illness also affected the time duration between visits.

I aimed to have a visit last approximately one hour, in consideration of couple's endurance to be engaged in these interviews and my own ability to be attentive to the situation. The interview length varied somewhat, and each couple responded differently to the questions and probes. One couple, for example, took more than 30 minutes to answer the demographic questions.

**Field notes.** Field notes were an aspect of the data collected and when relevant were added to the transcribed data. I developed a post-interview guide (see Appendix 9) to ensure that I recorded consistent information about each couple including my impression of their reaction to the visit. In my field notes, I noted aspects of the interaction that surprised me and observations about nonverbal behaviour of the PLWD or spouse that seemed significant during the interview. Field notes were written immediately after a visit.

### **Data Analysis**

I acquired an "intimate familiarity" with couples applying focused ethnographic method (Prus, 1996, p.9). As suggested by Knoblauch (2005) applying focused ethnographic methods led to acquiring data that emphasize the distinctiveness of responses related to the complexity of the



social situation of dementia that the intimate couples are embedded. The goal in making sense of the qualitative data is to describe patterned regularities in the data that can be used to describe the phenomena (Creswell, 2007). Finding patterned regularities amongst the couples' distinct responses led to discerning concepts that could be applied to describe what is happening in the relationship of intimate couples in their common situation of living with a medical diagnosis of dementia.

Finding patterns in the data began with the commencement of the field visits. First, I describe becoming familiar with and organizing the data (Braun & Clarke, 2006). Second, I describe how I applied a narrative approach to understanding the mutuality of the intimate couple. Third, I applied a thematic analysis as outlined by Braun and Clarke (2006) to interpret how couples express their shared understanding within the interaction.

### **Becoming Familiar and Organizing with the Data**

I listened to the audiotapes after the interview was conducted. I made notes on those aspects of the interaction with the couple that reflected their efforts toward mutuality. The tapes were sent to a transcriber. The transcripts contain a verbatim account of all verbal and nonverbal utterances. For example, I found that the transcriber consistently had added remarks that described nonverbal utterances such as "chuckling" within the text of the transcription. I added field notes from the post-interview guide to the specific part of the transcript that reflected the couple's efforts toward mutuality. I read and re-read the transcripts noting how each spouse in the interaction was making efforts toward mutuality. Adding the observations captured in the post-interview guide to the transcripts contributed a deeper sense of how mutuality was being expressed by the couple living in the context of dementia.

Determining if the transcripts were addressing the research question entailed asking an expert in qualitative research to review the transcripts. The first two interviews were reviewed by an experienced qualitative researcher, Dr. Donna Martin, a member of my committee and a professor in the College of Nursing at the University of Manitoba. Her review of the transcripts affirmed that interactions were conveying the couple's mutuality and sense of comfort with each other and affirmed that the data addressed the research questions. For example, within the joint interviews, ease of mutuality or difficulty in mutuality, a sense of comfort or discomfort in the interaction was identified.

Transcribed interviews were downloaded in Microsoft Word and NVivo 11 Pro. I started by using NVivo as a tool for data organization and management. I downloaded the transcripts. I identified how each person in the interaction described self, others, their relationship, events and everyday activities. For example, I applied 25 different nodes to the transcripts in NVivo. Examples of some of these nodes were 'descriptions of self,' 'descriptions of others', 'descriptions of relationship' and 'descriptions of everyday activity' and 'events'. I soon recognized how these descriptions occurred within the context of a larger story being told by one spouse or the couple. I also recognized the temporal nature of the stories. That is, some of the responses were referring to what was happening now within the immediacy of the interaction and others were referring to the couples past interaction. The changing circumstances in the interaction reflected the efforts toward mutuality occurring within the couple.

I used Microsoft office to write the stories coming out of the couples' interactions. This led to organizing the data into story topics and to gaining analytical insights about the common patterns of efforts toward mutuality. My advisor, Dr. Lorna Guse and I separately organized transcripts into story topics to ensure consistency in how the data was organized.

Stories occurred both in couples' descriptions of everyday activities and their shared relational stories. The transcripts were organized into sections by topic of the story being told. For example, a section of the transcript would be designated as describing changes in driving or a camping story. Included in analysis were interactions and responses of each person that was related to what was happening in the immediacy of the situation. These comments included "I will get you some coffee" or "I do not remember." These types of responses are discussed as being responses to the current situation.

The story-telling of each couple provided insights into the common patterns in what spouses said to each other and how the spouses spoke together. Distinguishable aspects of the interaction occurring in couple joint interviews were also identified by Torgé, (2013). These aspects were: the story, the textual elements and the interactive elements. Torgé (2014) identified the connecting piece of 'we-ness' in the way the narrative unfolded revealing how spousal couples with physical disabilities have mutuality in their caring. In the process of familiarizing myself with the data produced by the joint interviews of the couple in my study I recognized that what each spouse was saying and how they were saying it involved a sense making process. I noticed the PLWD was trying to make sense of who they were now by describing what they did in the past. I noticed that spouses of the PLWD were often trying to make sense of why the PLWD would no longer watch a special TV program with them or the PLWD could no longer help with taxes. Spouses were also engaged in supporting the narratives of the PLWD within the joint interaction (scaffolding). Hydén (2013) discusses the significance of and prompting the PLWD for their story. Therefore my interpretation of the spouse's listening and prompting was an important aspect of the analysis of the joint interview.

The intimate couples' unfolding stories about self, everyday activities and events (their narrative) revealed how each of the spouses was trying to make sense of themselves in the interaction in response to their changing context of dementia. What occurred during the narrative identified how each spouse was responding to the context of dementia through a sense making process. The context included both the symptoms of dementia (the extent to which memory impairment or communication difficulty was expressed in the interaction) and how the spouse responded to these symptoms (ignore, respond by scaffolding or provide cues).

Responses are observable relational behaviors in which the spouses convey their internal condition in reaction to their external situation or context of dementia (Hewitt & Shulmann, 2011). The nature of the acts (behaviors) were relational as suggested by Gubrium & Holstein (2008) in that their purpose was to make self and circumstances understandable to self so they could make sense to others. It is in the sense making within the interaction that meaning of self, everyday activity and the meaning of a story is changed. The meaning can lead to an increased shared understanding between the couple in their context of dementia. This sense making occurred in the joint interviews and the individual interviews and involved the PLWD or their spouse or both of them together conversing about past and present selves, relationship and/or everyday activity.

Answering research questions 1 and 2 involved applying thematic analysis to systematically describe the process for interpreting efforts toward mutuality in what each spouse was saying and how they said it. Responses reflected how the PLWD and their spouse were taking each other into account as they making sense of self, everyday activity, events and relationship.

## **Thematic Analysis**

Research questions 1 and 2 were answered in sequence. Codes and categories described the responses of each spouse as they conveyed their experience of shared understanding in the interaction. In answering research question 1, the individual responses most notably reflected how the relational self of each person was responding to the circumstances of dementia. According to SI the self –understanding developed is based on “self in relations to everyday life, in particular, the social interaction” (Gubrium & Holstein, 2008, p. 243). The relational self engages in the narrative process that develops the stories that express who we understand ourselves to be or our identities (DeMedeiros, 2014; Gubrium & Holstien). In answering research question 2, the unit was the interaction of the intimate couple whose responses shaped mutuality. These responses and the styles of interactions reflected the intimate couples’ efforts toward mutuality in the context of dementia.

**Applying thematic analysis.** Braun and Clarke (2006) identify stages of thematic data analysis. The first stage is identifying the basic element of the data into codes, the second stage is fitting these codes into categories, and the third stage is fitting categories into themes. Braun and Clarke discuss the systematic process of ensuring that themes represent the data. In my study, the consistency of the codes and categories and the themes were checked to ensure that the codes, categories and themes could be consistently applied to data and answered the research question.

### **Answering Research Question 1**

**Identifying codes.** Research question 1 asks how intimate couples respond within the context of dementia while discussing everyday activities, and their relational story, while interacting during routine activities and in novel activities. Answering this research question

meant identifying the basic elements of conversation (see Table 3) in the response of each person. In the interaction each person responds or acts towards another. As discussed in chapter 1, the response is the controlled observable behaviour describing interplay between the internal conditions of the person and external situation (including the response of the other) (Hewitt & Shulman, 2011).

Two studies provided background for an analytical process that led me to distinguish conversational elements of the responses (Radcliffe, Lowton, & Myfanwy, 2013; Torgé, 2013). These studies explored interaction occurring in joint interviews and distinguished the text (what was being said) from the interactive qualities (how it was being said) of the couples' interaction. There were variations and similarities in the textual analysis and the analysis of the qualities of the interactions. For example, Radcliffe et al. explored the creation of shared meaning and the implications for identity of spousal couples when one had experienced a stroke. Their study described textual elements as including argument, description and narration while interactive qualities were shifts in conversation. For example, textual elements were about one person describing what they did when they were providing care for their spouse. The interactive elements occurred as the shifts in conversation, for example when one spouse extended the idea of the other spouse, or questioned the spouse for information or answered questions that furthered the story or confirmed agreement ('um-hmm'). In another study, Torgé (2014) explored how the relationship of spousal couples who both experience physical disabilities shape their mutual caring, and the textual elements were those aspects of the text that describe 'we' and 'us' in the text. She describes this as distinct from the interactive data that conveyed couple's confirmation of each other or disagreement.

My analytical insights led me to identify both the text or ‘what was being said’ and the interactive qualities of the interaction in ‘how the couple are interacting towards each other’. Distinct elements of conversation were collated as the codes of defining, conversing and reviewing. Defining referred to how one of the spouses described something that defined self, other, relationship, activities or events. Conversing was the back and forth nature of the interaction between spouses. About 12 different elements of the conversing code could be identified. Reviewing referred to comparison in a temporal sense. The code ‘reviewing’ brings context to what is happening in the interaction by comparing past and present, or present and future.

**Table 3: Coding for the Elements of Conversation**

Codes	Elements of conversation
<b>Defining</b>	Describing self, other, relationship, activities or event
<b>Conversing</b>	
The couples engagement	Back and forth talk Turn taking  Only one person talking- not addressing the other for an extended time in conversation Inviting the other person into the conversation  Acknowledging the topic by repeating the words of the other or other verbal indications (mmm..)  Interrupting the topic Agreeing or disagreeing  Scaffolding: refers to the support provided by one spouse to the other in the story-telling.  Novel comment about the topic being discussed  Inclusive talk – ‘you’ or ‘we’ Exclusive language – talking as if the person is not there – using third person

	referencing 'he' or 'she'
<b>Reviewing</b>	
Temporal sense of response	A current situation Comparison of self, other, relationship, activity or event in present, past, or future Discerning if past, present, or future definitions of self, other, relationship or activity reflect a common understanding or an attempt to come to a common understanding or not.

**Identifying categories.** The codes of the elements of conversation: defining, conversing, and reviewing (See Column 1, Table 4, pg. 58) fit into the Level 1 category: a positive or difficult or neutral internal state (See Column 2, Table 4) or a recognizable or unrecognizable external situation (see Column 3, Table 4). 'Defining' was categorized as a 'positive' internal state when the comments describing self, other, relationship, event or activity had words expressing a positive understanding. In the 'conversing', 'positive' was applied when the couples were engaged in a topic together. In the reviewing, 'positive' referred to a consistency in the way self, other, relationship, activity or event was described between past and present or present and future.



**Table 4: Categories**

<b>Column 1</b>	<b>Column 2</b>	<b>Column 3</b>	<b>Column 4</b>
Codes – Elements of Conversation	Level 1 –Category Internal State  Positive/Difficult/Neutral	Level 1 – Category – External Situation  Recognizable/Unrecognizable	Level 2 –Category – Response  Familiar self/Unfamiliar self
<b>Defining</b>			
Describing self, other, relationship, activity or event	<b>Positive</b> in description of self, other, relationship or activity had words expressing a positive understanding of the self, other or activity.	<b>Recognizable</b> occurs when the description suggests what is being described is recognizable (not changed)	<b>Familiar self</b> of the spouse speaking
	<b>Difficult</b> when descriptions conveyed challenges or struggle.	<b>Unrecognizable</b> occurs when the description what is being described is not recognizable (changed)	<b>Unfamiliar self</b> of the spouse speaking
	<b>Neutral</b> when the describing text does not suggest either positive or negative		
<b>Conversing</b>			
How the couple engages; Back and forth Agreeing with each other Scaffolding (when one spouse responds by supporting the information being shared by the other) Novel comments  Inclusive or exclusive talk Including the other in the conversation or not including	<b>Positive</b> when engaged in topic together  Back and forth interaction Scaffolding Novel comments that are on topic Inclusive talk using pronouns of you or we Purposely including the other in conversation	<b>Recognizable</b> when the conversing is more positive	<b>Familiar selves</b> of both
	<b>Difficult</b> when not engaged together  Only one person talking Interruptions of topic Talking as if the person is not there  Using third person pronouns or referencing when the person is present – he or she	<b>Unrecognizable</b> when the conversing is more difficult	<b>Unfamiliar selves</b> of both spouses of the couple
<b>Reviewing</b>			
Temporal aspect of response as: Past compared to present Present compared to future Current situation	<b>Positive</b> when the descriptors or conversing related to the current, past or future are described as positive by both persons of the intimate couple	<b>Recognizable</b> when the review suggests a consistency in the external situation between past and present	<b>Familiar</b> self of the spouse
	<b>Difficult</b> when the descriptors indicate that self, other, relationship or activity was not as good as it had been in the past, for example	<b>Unrecognizable</b> when the review conveys an inconsistency in the current interaction or in the comparison between past and present	<b>Unfamiliar</b> self of the spouse

Defining was designated as 'difficult' when descriptions conveyed challenges or struggles that were inconsistent with the meaning of self, other, relationship, activity or event. In the conversing, responses were designated as 'difficult' when the couples were not engaged in a topic together, when one of the spouses was doing all the talking or when one of the spouses interrupted the other, including changing the topic. In the reviewing, the responses were identified as 'difficult' when something had changed and there were differences in shared understanding about the meaning of the change. Reviewing was also categorized as 'difficult' when the couples had differences in responses to their understanding of the changes from past to present or present to future. Defining was designated as 'neutral' when the comments describing self, other, relationship, activity or event expressed neutrality.

Interplay exists between the external situation and the internal state (in Level 1). This interplay acknowledges the external situation of the context of dementia. The category of recognizable external situation includes responses that conveyed the spouse's attention to the stability between their present external situation and their past external situation. Responses that conveyed the spouse's attention to the instability between their present and past external situation were identified as unrecognizable.

Responses in which the spouses conveyed a positive internal state were usually associated with their recognition of something recognizable or familiar in their current social situation. Responses in which the spouses conveyed a difficult internal state were usually associated with an external situation they did not recognize. Usually, the spouse was experiencing an external situation that had changed.

Level 2 categorizing involved fitting level 1 categories of positive/difficult and recognizable/unrecognizable into the categories of responses called the familiar and unfamiliar

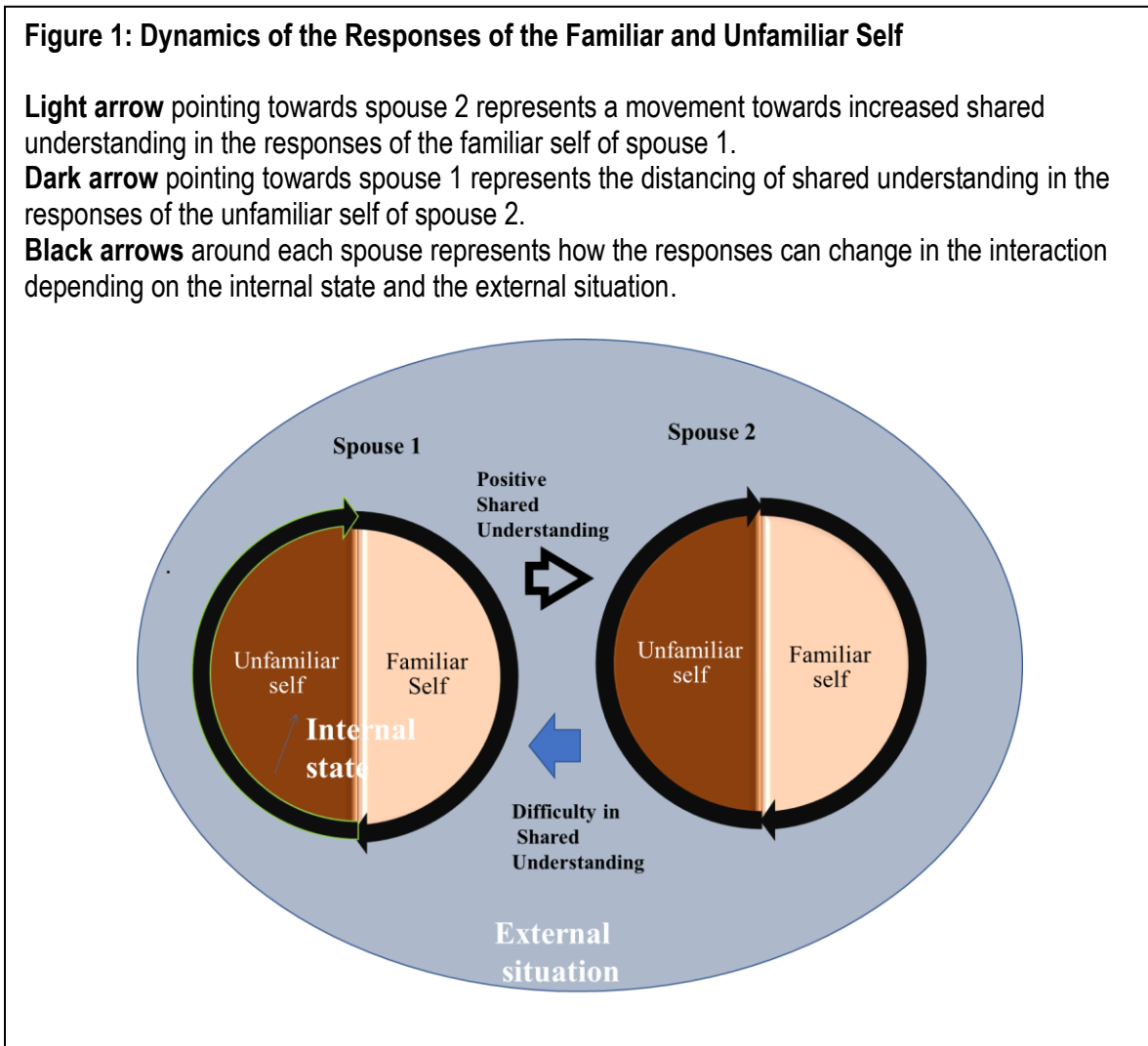
self. The responses of the familiar self identified an internal state as a 'positive' and an external situation as recognizable. Responses of the unfamiliar self were expressed as 'difficult' within the internal state and the external situation was unrecognizable. At times, the elements of conversation suggested difficulty in the internal state but the external situation was identified as recognizable. The external situation of the recognizable led to interpreting the response as a familiar self. These categories of responses of the familiar and the unfamiliar self reflected the extent of shared understanding conveyed by both spouses.

The category of the responses of the familiar self or the unfamiliar self were interpreted as conveying two different but associated messages about the couple's shared understanding. The response of the familiar self of the person was trying to move or increase shared understanding (or mutuality) between the self and the other. Mutuality as defined earlier in chapter 1 (definitions) involves a shared understanding about self, other, relationship event, or an activity (Prus, 1996).

The response of the unfamiliar self expressed distance in shared understanding with the other. The response of the unfamiliar self was also interpreted to mean that the self was in a process of reconciling self between past and present or between present and future. The categories of the responses of the familiar self or the unfamiliar self are not meant to suggest a static interpretation of interaction but rather an interpretation of the response of each person. The responses of the unfamiliar self or the familiar self may shift in the interaction in part to manage the ambivalences in shared understanding.

Figure 1 depicts the idea that is being conveyed in the level 1 and level 2 categories. The external situation and the internal state of the person shape the responses (moving the arrows) as the responses are encountered in the interaction. In figure 1, the response of the familiar self is

represented in the arrow going towards the unfamiliar self of the other. Spouse 1’s response is positively moving towards increased shared understanding while spouse 2’s response conveys difficulty in shared understanding. Overall, the responses suggest difficulty in shared understanding. However, interaction is dynamic; spouse 2’s response can change in response to the efforts of the familiar self of the other with of their external situation (context of dementia)



**Summary of Research Question 1**

Answering research question 1 involved discerning how responses of each spouse conveyed efforts toward mutuality of the couple as they answered questions about their everyday

activities and as they engaged in activity in the interaction. In doing so it was identified that the codes and categories needed to represent both the narrative (textual) and interactive data.

Question 1 was answered by breaking down the responses into elements of conversation. These elements fit into level 1 category expressing either a positive/difficult/neutral internal state or a recognizable or unrecognizable external situation. Both the internal state and the external situation of the responses are associated with each other. This association is captured in the level 2 categories of the response of the familiar self and the response of the unfamiliar self (see Figure 1). The responses of the familiar self reflect positive movement towards shared understanding with the intimate other; the unfamiliar self reflect difficulty in shared understanding with the spouse.

### **Answering Research Question 2**

**Fitting categories into a theme.** Answering research question 2 involved considering how the responses of the unfamiliar self and or the familiar self of the spouses shape the mutuality of the intimate couple. There were three different ways (styles of interaction) that the responses of the familiar self and unfamiliar self shaped the mutuality of the intimate couple. The different styles were: both spouses primarily had responses of the familiar self; one spouse had a response of the unfamiliar self and the other spouse had a response of the familiar self; and both spouses had responses primarily of the unfamiliar self. These styles of interaction conveyed efforts toward mutuality and were identified as: enhancing, maintaining and disrupting. The shifting responses or efforts toward mutuality result in a shifting of the styles of interaction.

**Description of themes.** Patterns of the categories of the responses of the familiar and unfamiliar self are described in three different styles of interaction. The three styles of interaction convey the expressed shared understanding in the responses of the spouses within interaction.

***Enhancing interaction.*** In the enhancing interaction, the spouses show primarily having responses of the familiar self. Both spouses are reinforcing or emphasizing their shared understanding in their life together. Mutuality is conveyed as each spouse moves towards a positive shared understanding in the interaction. An example of different enhancing interactions occurs when the intimate couple shares memories, describes shared activities or, in some instances, describes significant memories or activities.

***Maintaining interaction.*** In the maintaining interaction one of the spouses have responses of the familiar self and the unfamiliar self, or one spouse changes from a response of the unfamiliar self to a familiar self. Two different types of maintaining interactions are identified. One is a mending interaction, and the other is a preserving interaction.

***Preserving interaction.*** In this interaction one of the spouses suggests that they are preserving an understood mutuality of the past and reinforcing its value in the current circumstances. I suggest that this spouse is preserving an understood mutuality of the past and reinforcing its value in their current circumstances.

***Mending interaction.*** In this interaction one of the spouses' responses suggest that they are reframing the meaning of an everyday activity or event. The spouse's response suggests that this reframing involves an increased awareness and acceptance (accommodation or adjustment) of what it is to live in relationship with dementia. The interaction is usually a description of how an everyday activity has changed. A response that suggests the reframing of an activity could simply voice their acceptance of the change by stating 'it's OK.'

***Disrupting interaction.*** In this interaction, both the spouses have responses that are primarily the unfamiliar self. Both are having difficulty understanding the self, other,

relationship, activity or event in this current context and both spouses express a lack of shared understanding about the meaning of self, other, relationship, activity or event.

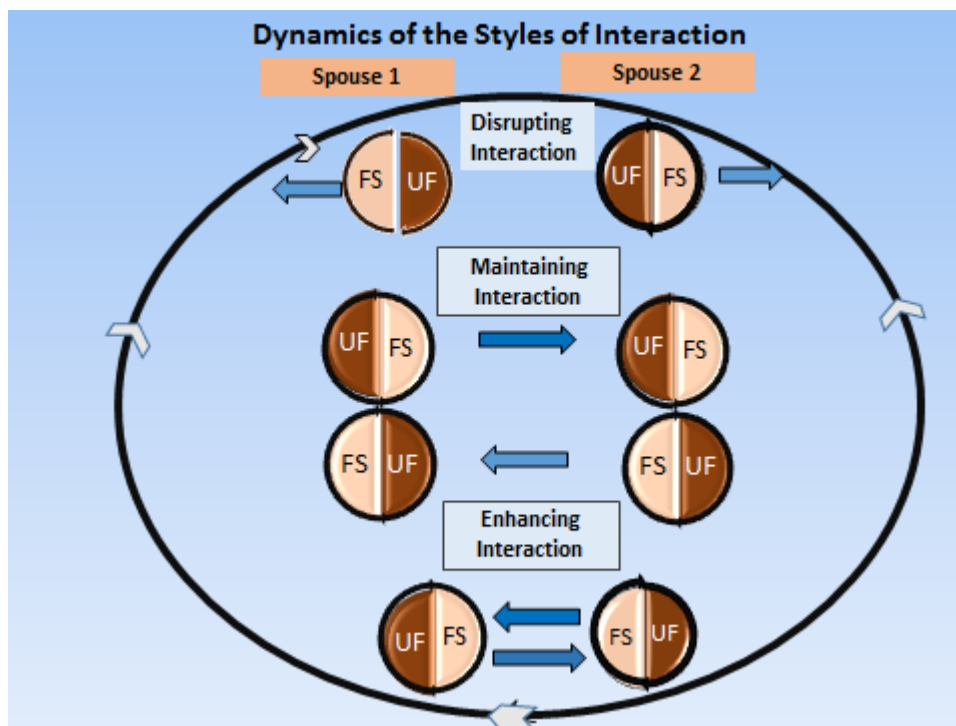
### **Summary of Research Question 2**

Answering research question 2 involved fitting the categories of the responses of the familiar and unfamiliar self into the themes of styles of interactions. Responses were the efforts toward mutuality conveyed in the responses of the familiar and unfamiliar self. Efforts toward mutuality were described in the styles of interaction: enhancing, maintaining and the disrupting.

The findings described through the process of thematic data analysis are an analytical framework that can be applied consistently to describe how the intimate couple makes efforts toward mutuality (Figure 2, pg. 68).

**Figure 2: Dynamics of the Styles of Interaction:** Describes efforts toward mutuality and the dynamics that occur between the spouses. In this figure, the analytical framework of my study is conveyed as follows:

1. The responses of the relational self of each spouse are represented in the circles by UF (responses of the unfamiliar) and the FS (responses of the familiar self).
2. The styles of interaction are represented in the different patterns of UF and FS facing the other.
3. The arrows depict the direction of the efforts toward mutuality.
  - a. In disrupting the arrows go away from each other,
  - b. In maintaining, the arrows indicate how one spouse is moving towards the other and the other spouse is going away from the other.
  - c. In enhancing style the arrows go towards each other.
4. The outer circle is the context of dementia, those external situations interplaying with the internal states of the self.
5. The arrows going around the inner circles represent the possibility of changing responses of the familiar and the unfamiliar self to the external situation
6. The arrows around the outer circle represent the ongoing possibility of changing context influencing the external situation.





### Examples of Data Analysis

The following two excerpts of transcripts and their analysis depict how data was organized and analyzed using the analytical framework. The codes and categories of the couples' responses are displayed in a table (see Table 5 and Table 6) and the styles of interacting based on the analytical framework are described after the excerpt. The first excerpt, Paul and Elizabeth, is an interaction in which there is an exchange about everyday activities; the second excerpt, Emmanuel and Karen, is an exchange that occurred within the description of a relational story.

**Paul and Elizabeth.** This excerpt occurred in the first joint interview between Elizabeth and Paul. The focus of this interview is how everyday activities have changed or not changed for the couple in the last few years. Up to this point in the interview, Paul had done most of the talking. Now Elizabeth has begun the discussion about everyday activities by comparing her current experience caring for her husband (PLWD) to her previous experience caring for her mother who had recently passed away. Elizabeth started by reflecting on her current caregiving challenges. Completing taxes was the activity that she used to exemplify how everyday activity had changed:

**Elizabeth:** *And so I kind of got into a routine of looking out for someone and so it just sort of carried on with Paul, except that my mother was very sharp mentally but had arthritis and a degenerative heart.*

**Researcher:** *But at 102, wow (chuckle) a little bit of arthritis and a heart problem.*

**Paul:** *She was a beautiful woman.*

**Researcher:** *Yeah.*

**Paul:** *Just a beautiful woman.*

**Elizabeth:** *So I'm left with the challenge of how do I help Paul get the most out of life and I struggle between having him do something for himself or doing it for him because I could do it faster and better. And then I see him wanting and I'll just use income tax or he'd want to be knowing what's happening, read it, put it somewhere, not know where he's put it.*

**Researcher:** *Okay.*

**Elizabeth:** *And we need to turn it in and he'll forget that he's read it, he has no recollection that he's read it and I struggle between, yeah you, you want to read it but you know two days later you, you'd want to read it again 'cause you don't know it but in*

*the meantime you've put parts of it and so then we're left scrambling or I'm left scrambling trying to make sure we've got all the pieces still because each time we miss something out in putting it back.*

**Researcher:** *Yeah.*

**Elizabeth:** *...it, it truly is. And sometimes we're, we're good at doing it and sometimes we're not so good at doing it, but he'll want more.*

**Paul:** *Yeah.*

**Table 5: Applying codes and categories to an Excerpt from Paul and Elizabeth**

Coding: Elements of Conversation		Category1: Internal state	Category1: External situation	Category 2: Responses
<b>Defining</b>	Examples	Positive or Difficult	Recognizable or/ Unrecognizable context	Familiar or Unfamiliar self
Elizabeth describes herself.	Elizabeth describes herself as struggling, scrambling and helping Paul get the most out of life.	Difficult	Elizabeth responding to an unrecognizable context	Unfamiliar self of Elizabeth
Elizabeth describes her husband.	Elizabeth describes her husband as wanting and forgetful.	Difficult	Elizabeth responding to unrecognizable context	Unfamiliar self of Elizabeth
Paul describes his mother-in-law	Paul describes his mother-in-law as beautiful	Positive	Paul responding to the recognizable context	Familiar self of Paul
Elizabeth defining their relationship	as good and not so good.	Positive	Elizabeth responding to the recognizable context	Familiar self of Elizabeth
Elizabeth defining activity	Elizabeth describes doing taxes has having lots of pieces to keep track of.	Difficult	Elizabeth responding to the unrecognizable context	Unfamiliar self of Elizabeth

<b>Conversing</b>				
<b>Not engaged in topic together</b>	Elizabeth does most of the talking  Elizabeth refers to Paul in the third person “he”	Difficult	Elizabeth responding to the unrecognizable context	Unfamiliar self of Elizabeth and Paul
<b>Engaged in topic together</b>	Paul agrees with Elizabeth “yeah”	Positive	Paul responding to the recognizable context	Familiar self of Elizabeth and Paul
<b>Reviewing:</b>				
Talk is comparing past to present	Changes in how they used to do taxes and how they do them now  Changes in how Elizabeth sees her husband “wanting”  Changes in how their relationship is now and how it was	Difficult	Unrecognizable context  Present in relation to past	Unfamiliar self of Elizabeth

*Responses of unfamiliar and familiar self.* In the excerpt, Elizabeth’s responses are categorized primarily as the unfamiliar self, while Paul’s responses are categorized as the familiar self. Paul’s responses of the familiar self involve his attention to his recognizable relationship with Elizabeth rather than the changing dynamics of their everyday activity being described by Elizabeth. His responses reflect an attempt to find a common or shared understanding with his wife presenting himself as positive and agreeable to his wife.

Elizabeth's responses are the unfamiliar self because she describes the difficulties she has and she does not engage her husband in the discussion. In the discussion she reviews her situation and identifies the changes she encounters as changes between her past understanding of herself and her husband, and the way that everyday activities were conducted. The current situation, the way they now do taxes, is not a recognizable aspect of their shared life together. Elizabeth does not convey an understanding of how Paul might be experiencing her comments. In this interaction her responses of the unfamiliar self suggest difficulty she is having with a shared understanding with her husband.

*Style of interaction.* The style of interaction occurring in this excerpt is described as maintaining because Paul makes a few responses of the familiar self and Elizabeth has responses primarily of the unfamiliar self. In the interaction Paul's responses of the familiar self move the couple's mutuality positively. Elizabeth expresses the difficulty she is having in the current context of dementia. She does not engage Paul in her description. In this interaction it is suggested that Paul is preserving the interaction by establishing his sense of self by bringing up something about their past situation that was positive (his beautiful mother-in-law). With at least one spouse expressing positive efforts towards even a previously understood mutuality, this interaction is described as maintaining mutuality.

**Emmanuel and Karen.** This next excerpt, an interaction of a relational story between Karen and Emmanuel, was considerably different from Elizabeth and Paul's interaction. The context of the interaction is different in that I have asked Karen to tell me a story about something that happened recently to both of them. The dementia context is different also, as Emmanuel is further along in the dementia journey compared to Paul. Karen and Emmanuel engage in conversation while they are being photographed:

**Researcher:** *So what I'm going to do is take a bunch of pictures while you two talk.*

**Karen:** *What should we talk about? Is there something special? I'm just trying to think of something fresh in his mind.*

**Emmanuel:** *(Chuckle)*

**Karen:** *'Cause his history doesn't come up too much. What about, do you remember we were just at the cottage?*

**Emmanuel:** *Yes.*

**Karen:** *Just a few days ago, yeah.*

**Emmanuel:** *Um-hmm.*

**Researcher:** *Oh that's nice.*

**Karen:** *Okay. And who was with us at the cottage?*

**Emmanuel:** *Who was there?*

**Karen:** *Who was with us?*

**Emmanuel:** *Well there were some of our children.*

**Karen:** *Um-hmm.*

**Emmanuel:** *And yeah, we were blessed by having them wanting to be with us.*

**Karen:** *That's right.*

**Emmanuel:** *And, and we enjoyed having them. And there are several of these things.*

**Karen:** *Um-hmm.*

**Emmanuel:** *Yeah.*

**Karen:** *What about the two fuzzy creatures that were with us (laughter).*

**Emmanuel:** *Are you suggesting that you are...*

**Karen:** *A fuzzy creature?*

**Emmanuel:** *Well my dear.*

**Karen:** *I hope I'm not too fuzzy a creature.*

**Emmanuel:** *No.*

**Karen:** *Do you remember which the fuzzy creatures, who the fuzzy creatures were.*

**Emmanuel:** *Hmm, um-hmm, well we have very very kind and gentle animals.*

**Table 4: Applying Codes and Categories to an excerpt from Emmanuel and Karen**

<b>Coding:Elements of Conversation</b>		Internal state	External situation	Response
<b>Defining</b>	Example			
Emmanuel describing himself and Karen	We were blessed	Positive	Emmanuel responding to recognizable context	Familiar self of Emmanuel
Karen describing event	Weekend at cottage	Neutral	Karen responding to recognizable context	Familiar self of Karen

<b>Conversing</b>				
Not engaged in topic together	Karen referencing Emmanuel in third person “his mind”	Difficulty	Karen responding to unrecognizable context	Unfamiliar self of Karen and Emmanuel
Engaged in topic together	Back and forth comments  Humourful interaction	Positive	Couple recognize context	Familiar self of Karen and Emmanuel
<b>Reviewing</b>  Talk relates to current situation	Emmanuel and Karen talking about what happened at the cottage	Positive	Recognizable context between past and present	Familiar self of Karen and Emmanuel

*Applying the unfamiliar and familiar self.* Karen’s responses are both the responses of the unfamiliar self and the familiar self. Karen has the response of the unfamiliar self while thinking about what to talk about. She briefly talks about Emmanuel and not with Emmanuel. Emmanuel’s agreeable responses to her comments engage both of them for most of the interaction as responses of the familiar self. They are both on topic together; there is humour in their engagement with each other. Karen tries to understand what Emmanuel is saying when he responds to talk about the “fuzzy creature.” Karen fosters Emmanuel’s continued relational self. Emmanuel’s continued social abilities are also evident. Their interaction was a current interaction; there was no discussion of how it reflected a past or future experience or activity. The responses of the familiar self of both of them convey that the current context in which the conversation is occurring is recognizable to them both.

*Style of interaction.* The type of interaction occurring between Emmanuel and Karen is enhancing: both make comments that express a positive mutuality towards the other, thus enhancing their mutuality. Karen recognizes her husband's responses within the context of dementia and has accommodated her responses to maintain the mutuality possible within the couples' verbal interaction. Though Karen initially begins the conversation by talking about rather than with Emmanuel most of the interaction expresses their shared understanding. They are two familiar selves.

### **Summary of the Process of Data Analysis**

The initial process of familiarizing myself with the data led to recognizing the narrative process in the interaction of the couples. In this narrative process the intimate couples seemed to be attending to each other by talking about the past often in positive ways and describing their difficulties in the present. For example, when PLWD described a stories about being successful in the past, it seemed to reflect their interest in wanting to be recognized this way in their current relationship. They were making efforts toward mutuality by reminding others of who they were in relationship and how they wanted to be in relationship. When the PLWD or their spouse's message suggested difficulty with self, relationship or everyday activity, this was an effort to resolve the meaning implied in the interaction suggesting that self, everyday activity or relationship was no longer what it had been. It was an effort for the intimate couple to figure out or to make sense of who the PLWD was and who their spouse was now and how they were in their relationship within the context of dementia.

The procedures of thematic analysis were applied to the joint and individual interviews to systematically interpret the interaction to answer the research questions. Research question 1 directed attention to analyzing the common features of the responses. These were identified as

codes called the elements of conversation. The second process involved fitting these codes into categories. There were two levels of categorizing: Level 1 and level 2.

The level 1 categorizing divided the elements of conversation into an internal state describing the defining, conversing or reviewing as conveying either a positive, neutral or a difficult internal state. This level 1 categorizing also involved identifying how the external situation of the context of dementia was being conveyed in the interaction. The external situation was either a recognizable context or an unrecognizable context. The level 2 categorizing fit the internal state and response of the external situation in one category, the familiar or unfamiliar self. The unfamiliar self contained the difficult internal state and the unrecognizable context. The familiar self conveyed the positive internal state and the recognizable context.

The second research question asked how the responses were shaping the mutuality of the couple. The mutuality of the couple is expressed in their style of interaction. Procedures of thematic analysis were employed by applying the categories of the familiar and the unfamiliar self and discerning pattern describing the style of interaction was discovered in the joint and individual interviews. The different styles of interaction were: disrupting interactions; maintaining interactions, including preserving and mending interactions; and enhancing interactions.

### **Rigor of the Study**

Demonstrating the rigor of my study involves describing the systematic practices conducted throughout the research process that verifies the validity of my data (Hesse-Biber & Levy, 2011). The rigor of the research findings is demonstrated in the credibility of the process I used to interpret the participants' accounts (Creswell, 2013; Hesse-Biber & Levy, 2011). This



credibility is identified in the methodological process applied to understand the intimate couples' effort toward mutuality. The demonstrated rigor of my study is an important aspect of the contribution it makes to the literature and to the practical application to health care problems (Tracy, 2010).

My study, most prominently, attained rich and varied data to answer the research question. Symbolic Interactionism and the narrative approach contribute to the rigor of the study because they were applied to both data collection method and the data analytical process. The assumptions of SI and the narrative led to close attention to the interaction and consideration of methods that would encourage and support an understanding of the couples' efforts toward mutuality. The strength of using these two approaches is that it directs attention to the whole interaction as a context for understanding the responses of the PLWD. It puts the text in the context of the story of the couple. A limitation applying these approaches used to understand the couples' efforts toward mutuality is its reliance primarily on text of the interaction. Though field notes were included in the analysis of the interaction, field notes were limited in the collection of nonverbal behavior of the couples. Application of theories of embodiment could have furthered the understanding of the couples interactions and accomplishment of everyday activity. Photographs and field notes could have analyzed for the expression of expression of the couples embodied shared understanding.

Recruiting participants who were living as a couple dealing with the consequences of dementia who were willing to speak to me about their everyday experience living with dementia as well as provide stories from their past or more recent experiences was a significant aspect of collecting rich and varied data in this study. Participants in this study demonstrated openness about their circumstances. However, the homogeneity of the group might have limited the type

of data collected. The couples represented a similar socio-economic group of Caucasian, English as-a-first-language background and were partners in a long term heterosexual relationship. More importantly, couples who agreed to participate in the study were probably those who had an inclination towards making positive efforts toward shared understanding and mutuality. The strong bond between the intimate couples provided insight into the varied ways spouses support each other in the context of dementia. Couples who had a heightened sensitivity to dementia related to stigmatization or who were having difficulty overcoming disrupting interactions related to dementia would have been less likely to participate in the study.

Collecting rich and varied data was also related to my choice of focused ethnographic methods. The rigor of my study is demonstrated because of the “extensive data collection in the field” (Creswell, 2007, p. 46). Collecting extensive data involved three to five different field visits with each couples. A number of approaches to optimize opportunities to learn how each couple made efforts toward mutuality in the everyday activities including their interactions. Triangulation of methods included one joint semi-structured interview and at least two interviews with each couple that were guided joint interviews. Joint interviews were identified as the method to best acquire an understanding of how intimate couples make efforts toward mutuality and contributed to the strength of the study. Semi-structured individual interviews were conducted with 7/8 intimate couples. Strength of this study was to use routine and novel activities to simulate varied types of interactions that couples might have in everyday activity. In routine and novel activities guided interviews were conducted. During one of the guided interviews I engaged having coffee and a snack with the couple. In another, I asked if I could take their photograph while they continue to talk together and enjoy their coffee. Though only six of the eight couples agreed to be engaged in photographing I spent additional time with them

engaged in guided interactions. The strategies of being a participant-observer or observer-participant contributed to setting up situations that captured the different ways couples related. The different positions I took as a researcher and the different activities of the intimate couples engaged contributed to attaining data that facilitated knowing the intimate couples' efforts towards mutuality.

During field visits with the couple I acted to promote the interaction between them by asking questions that either or both the PLWD and the spouse could answer and by encouraging their discussion on a topic. Researchers suggest that the data collected using joint interviews could lack depth related to couple desirability I found strength in the use of joint interviews (Zarhin, 2018). Although the joint interview might limit what each PLWD or their spouse is comfortable discussing in other's presence I found couples very open in the joint interview. Strategies used by the intimate couple to respond to tensions that arose were an aspect of the recognizing their efforts toward mutuality.

I was concerned that PLWD communication difficulties might decrease an understanding of their efforts toward mutuality. However, even when the PLWD was far along in the dementia journey, their engagement in social interaction was noteworthy. Both the spouses and the PLWD had agency in the interaction and responded as partners when making decisions about how to have their photograph taken or which photograph to choose. One of the strengths of combining joint and individual interviews was that this helped in identifying the subtle ways in which the spouses were scaffolding the interactions with the PLWD in the joint interview. As suggested by Tolhurst et al., (2017) the joint interview offered insight into interactions that provided a balanced perspective on the normal exchanges of the couple. For example in my study, one spouse avoided implying that her husband had dementia or memory

problems within the joint interview. This approach was one strategy she took to enhance the mutuality between her and her husband. Studies discuss the potential harm that could occur if and when couples have conflict in the interaction. Facilitating the couples' dual dialogue and focusing on the positive strategies that couples' used to engage and support each other may have overcome situations in which the couples were left disenfranchised. This is consistent with the conclusion derived by Voltelen et al., identifying that "hurtful matters helped the participants enhance their coping strategies and created a sense of cohesion" (p.521).

Conducting semi-structured individual interviews contributed to the strength of my study by reinforcing the validity of the observed efforts toward mutuality in the joint interviews. In addition, the individual interviews added insight into efforts toward mutuality that were not expressed in the joint interview. PLWD and spouses' individual interviews were varied and contributed to an understanding of each of their efforts toward mutuality in the way they described and understood their interactions. For example, one of the PLWD, Evelyn, seemed to enjoy the opportunity to speak in the individual interview about the difficulty she was experiencing with her husband. I was surprised that two PLWD were uncomfortable with having the individual interview with me but it supported the very significant role of the spouses in each couple. In the individual interviews, I found that spouses' reflections on their experiences led them to express a deepened understanding and commitment to their PLWD.

Alternative procedures for data collection might have captured different ways in which couples made efforts towards mutuality. I could have left the couple alone with an audio-tape for at least one of the interactions in which they discussed their everyday activities or a relational story without my presence. I might have heard a different type of engagement during interactions in which the couple spoke more privately to each other.

Taking photographs of the couple and photo-selection was meant to engage the couple in a decision making process interaction. Six out of eight couples participated in the activity of being photographed, and photo-selecting with photo-elicitation. Couples often selected to pose for photographs. The couples were encouraged to continue talking, but the camera often captured their attention and took away from the interaction I wanted to capture. The activity of photographing was much more stilted than I had imagined, as the couple generally posed rather than continuing with their activity. Alternative forms of collecting data for this research could have included video-taping interactions which might have allowed for a more in-depth analysis of nonverbal behaviour. Another approach would have been to use photo-voice, asking the couple to photograph each other, or items of significance, while they participated in their everyday activities. The descriptions of the photographs they took might have produced additional insight into how spouses understand each other and their everyday activities.

Rigor of the findings, and most specifically, the collection of rich and varied data, reflected the self-reflexive process undertaken throughout the data collection process and analytical process. This process involved documenting aspects of the field experience that I had anticipated and that had surprised me. Self-reflexivity heightened my awareness of the ethics in the data collection process. I wanted the PLWD and the spouse to feel valued as participants and persons.

Respect and value involved considering the voice of each intimate couple in the research process and is exemplified by the changes I made to accommodate for the individual situations of the intimate couples. For one couple, I had five visits, two of these visits involved talking to the spouse alone. This couple did not want to have photographs taken, however, we had coffee together as a group twice. For another couple, I sensed that the spouse was participating because

of the PLWD interest in being involved in my study. For this couple and others, I considered the burden of having to accommodate a visitor to their home and decided to combine activities for fewer visits to reduce the stress on the couple. Respect and value of the voice of each participant was also reflected in my process of data collection. My attention to the interaction and the emotions expressed during these interactions was an important aspect of the data collection process. At these times I allowed for silence. I did not direct who should talk, but allowed the participants to express their own voice at their own time. Listening to the nuances of the interaction that reflected how each person was making efforts toward mutuality was an action I took to facilitate their engagement and to show respect (Hesse-Biber & Leavy, 2011).

Rigor is demonstrated in the analytical process I used to move from multiple simple statements about the data to higher levels of abstractions to describe the data. The analytical process I undertook was meant to highlight the voices of the intimate couple. It was meant convey their social reality. Using different methodological processes aided on capturing a wholistic understanding of the intimate couples' circumstances living in the context of dementia. Symbolic Interactionism guided a consideration of what was happening in the interaction related to shared understanding in the interaction of the couple. The narrative approach focused on the retrospective content occurring in the narrative. I applied these approaches as discussed by Gubrium and Holstein (2008). I reflected on how each person's expression of their social self was an attempt at times to make self understandable to self and to the other (their spouse). In making self understandable to the other and to self, each spouse was trying to adjust and increase their shared understanding with the other in the interaction.

Rigor was illustrated in my study because the accuracy of accounts of the participants was validated through peer checking of participants' accounts, member checking and

triangulating sources of data (Creswell, 2007). The credibility of the data analytic process to convey the intimate couples' account of their efforts toward mutuality was supported with procedures that demonstrate the consistency of categories and themes across couples. Braun and Clarke (2006) refer to two procedures done to ensure the internal and external homogeneity of findings. Internal and external homogeneity refer the coherence of the data within the themes (internal) and whether the data represents a distinction between the themes (external). The procedures described by Braun and Clarke involve taking into account all the data first to see if the themes capture the data, and secondly to discern if they accurately represent the data. Dr. Guse, my advisor, worked independently to organize the data across the data set. Dr. Guse coded and categorized the responses of the familiar and unfamiliar self for the first interview of four different couples and applied themes across three joint interviews of different couples. Internal and external homogeneity was also suggested when checking with other committee members because they agreed with the consistency and conceptual clarity of the categories and themes developed to describe the data. Two subthemes (preserving and mending) were recognized in the process of consulting and discussing the theme of maintaining.

Member checking is a procedure to validate findings of studies (Creswell, 2013). In my study, two participating intimate couples were consulted to gain their perspective on the analytical framework I developed to describe interaction in this study (similar to member reflection in Tracy, 2010). The two couples agreed that the framework made sense in describing their interaction. In conducting the member checking, however, I noticed that one of the PLWD focused on his lack of recollection of the research activity and the other PLWD talked about his current feelings of despair (and these expressed feelings had an impact on the spouse). Although “additional data or an elaboration of information” (Tracy, 2010, p. 844) can be obtained during

member reflection, in some cases, sensitive consideration of the utility of this approach needs to be balanced with the potential for causing difficulties. I would be cautious about using member checking in the future.

### **Summary of Chapter 3**

This chapter described the methods I used to collect and analyze the data to answer the research questions. The principles of focused ethnographic methods were applied in this study to facilitate acquiring an emic perspective. More specifically, focused ethnographic methods facilitated learning how different intimate couples respond to the complexity of living with dementia. Collecting in-depth data involved time limited, short, intense periods of field work with each couple. Applying focused ethnographic method in this study recognizes the role of the researcher in the data collection and analysis process. It included applying diverse approaches to facilitate the couples' engagement with each other. Approaches including engaging in routine and novel activities such as photo-elicitation are unique. Applying these approaches is consistent with the application of the goals of focused ethnography to "collect descriptions of people's ways of life and their increasingly specialized and fragmented activities" (Knoblauch, 2005, p.2).

Focused ethnographic methods supported the identification of the unique and varied ways that intimate couples come to understand and live with their circumstances. It led to an analytical process that acknowledged similar patterns among interactions between couples but also recognized that each couple was distinct in how they came to live with their own circumstances. Consistent with this method, I described the reflexive process I engaged to make the research process transparent. Focused ethnographic method incorporates an understanding that the researcher is knowledgeable in the field of study. I described the extent that I am aware of and understand that this knowledge shaped the data collected and the analytical process that



occurred (Knoblauch, 2005). The position of the researcher as participant-observer and as observer-participant in the data collection process of this study was discussed.

The procedures of data collection were described as accessing the field and field visits. The procedures for accessing the field entailed attaining ethical approval, sampling procedures, inclusion criteria and recruitment. The procedures for field visits included describing ethical procedures during field visits and the research activities that were engaged in the data collection process. As well as participant-observation, data collection included, joint interviews, semi-structured interviews, guided conversation and individual interviews. All formal interviews and guided conversations were conducted by the researcher and audio taped. Audio-tapes were transcribed verbatim.

Data analysis included becoming familiar with the data, organizing the data, applying a process of thematic analysis that led to describing types of responses and the interaction. The process of becoming familiar with the data led to consulting the literature and the development of an analytical framework that answered the research question. The narrative approach identified how the responses of the familiar and the unfamiliar together are responses that describe the efforts toward mutuality in which each spouse of the couple attend to the other while making sense of self, relationship and everyday activity. Patterns of these responses describe the styles of interactions: enhancing, maintaining and disrupting. Example analysis was applied to two different excerpts.

In my study, I had sufficient rigor to warrant that findings be considered trustworthy. In particular, I had rich and varied data to explore the intimate couples' efforts toward mutuality. Acquiring rich and varied data was associated with the couples' openness, my prolonged engagement in the field and triangulation of methods. Self reflexivity also aided in acquiring and

interpreting rich and varied data. The analytical process involved applying 2 different approaches: SI and the narrative approach. The developed themes and categories were checked for internal and external homogeneity with my advisor and committee members. Member checking procedures were conducted, but on reflection might be less appropriate in studies such as mine. The processes undertaken to ensure the internal and external homogeneity of the categories and themes facilitated developing concepts that other researchers might see as transferable to other situations.

Chapter 4 and 5 describe the findings. Chapter 4 describes the answer to research question 1. Findings include how the self of the PLWD attends to the relationship with their spouse through responses of the familiar and unfamiliar self. In the second section of Chapter 4, answering research question 1 illustrates the finding that the everyday activities of the intimate couples are the hinge upon which the PLWD and their spouses attend to each other in their responses of the familiar and unfamiliar self.

Chapter 5 answers research question 2. In the first section, findings illustrate how the responses of the familiar and unfamiliar self shape the mutuality of the intimate couple. Findings illustrate the different styles of interaction that reflect the mutuality of the couple in the immediacy of the interaction. These different styles of interaction reflect the direction of mutuality or shared understanding in the interaction (see Figure 2). In the second section of Chapter 5, further application of the analytical framework to different interactions of the intimate couple present the analytical framework as a guide to discern those features the context of dementia that shape the mutuality of the intimate couple.

#### **Chapter 4**

##### **Findings: Research Question 1**

In this chapter I describe the answer to research question one: How do intimate couples living within the context of dementia respond to each other, while discussing everyday activities and describing their relational story and while interacting during routine activities and novel activities? Intimate couples living within the context of dementia respond to each other by shifting responses of their familiar and unfamiliar self. Responses of the PLWD convey their continuing abilities within the interaction and their relational agency. The responses of the familiar self of each spouses (PLWD and their spouse) conveys their attempts to move towards their spouse in their increased shared understanding (or mutuality) in the interaction. The response of the unfamiliar self of each spouse conveys their difficulty in shared understanding with their spouse.

The shift in the responses of each spouse is understood to be a relational process occurring in the interaction (De Medeiros, 2014; Gubrium & Holstein, 2008). Sense making is a process in which the PLWD and the spouse sort out ‘who I am in the interaction including who I am as a distinct human,’ and ‘how I know who I am in the interaction’ and consequently, how I fit into society (De Medeiros, 2014; Gubrium & Holstein, 2008). In making sense of self they can bring a sense of continuity of self or an unresolved self to the interaction in their context of dementia. The context of dementia is the circumstance in which the intimate couples currently live; changes occur during meal making, walking, conversing, decision making and conflict management and with what the intimate couple had previously taken for granted as shared understanding in their relationship. The shifting responses of the familiar and unfamiliar self in each couple’s interactions occur in each couples’ distinct context of dementia. The shifting

response of each spouse in the interaction occurs as each spouse in the interaction makes about self and their everyday activity.

There are two sections answering research question 1. The first section describes the shifting responses as they reflect the sense making of self of the PLWD. The second section describes the shifting responses as they reflect the sense making of everyday activities. The distinct context of each intimate couple is described prior to sample excerpts from that couple which depict their shifting response. The couples name is introduced prior to the excerpt. The PLWD is always listed first. There are a few excerpts from the individual interviews of the PLWD or their spouse. When it is not a joint interaction, I indicate in parenthesis that the excerpt comes from an individual interview. Each of the excerpts has been analyzed to consider how the responses convey the responses of the familiar self or responses of the unfamiliar self. Three sample excerpts are provided in Appendix 10 and outline the analytical process. Field observations are bracketed and bolded.

### **The Shifting Responses of the Self**

The sense making efforts of the PLWD in the interaction are significant and are expressed in the shifting responses of the unfamiliar and familiar self of the PLWD. Shifting responses of the PLWD also highlight their agency or their ongoing ability to give voice to who they are and how they fit in relationship. The responses of the PLWD occur within their distinct interactions with their spouses. Several of the PLWD most notably convey their sense making and their sense of continuity between past and present. The PLWD responses of the familiar self is often associated with past roles. In their description of past roles they express a sense of continuity occurring in the immediacy of the interaction. In describing their present situation however, the PLWD often expressed difficulty in their continuity of self. They had responses of

the unfamiliar self, expressing a current unresolved self. Other PLWD had shifting responses that were explicitly attached to their interaction and sense of connection with their spouse. It was clear that their responses of the familiar self expressed how their relationship was an aspect of maintaining their sense by knowing who they were in relationship.

Excerpts from six couples illustrate responses of the familiar and unfamiliar self. After each of these excerpts, I describe how the shifting responses of the familiar and unfamiliar self convey sense making in their continuity of self or in their expression of an unresolved self. I discuss how these responses express their attempt to make efforts toward mutuality within the interaction.

### **Tom (PLWD) and Mary (Spouse)**

Tom and Mary had been married for 57 years and have two sons. Tom was 83 and Mary was 78. Tom had mild vascular type dementia. He was diagnosed by a neurologist a year-and-half prior to the interview. Mary had noticed changes in Tom's memory over 3 years ago. Neither Mary nor Tom had noticed significant cognitive changes or difficulties since this diagnosis. Mary talked about Tom having dementia and Tom described himself as having a short memory problem but did not refer to having dementia. Tom and Mary describe themselves as fairly healthy and active. They were both mobile and were able to walk long distances. They live in a well kept bungalow in a suburban neighborhood. One of their sons lives in Winnipeg. The interviews were conducted in the living room of Tom and Mary's home. When the intimate couple were being interviewed Mary sat across from me and Tom sat in a chair between us.

In the following four excerpts Tom's brings attention to his past achievements. Tom's responses are describing how he experienced himself in the past and how he is experiencing himself now:

In the first excerpt, Tom is recollecting his past as he responds to questions about his career:

**Tom:** *We both realize we both had a specialty and like, like some of the jobs I got into, well I'll show you all the stuff that I picked up, and I picked up basically because of the background I grew up in. Cause I was able to take charge and do things. I was the one that did the write-ups, I did the reports.*

**Researcher:** *Interesting.*

**Tom:** *But I did a German course or I made a presentation at the American airbase what my views were on the way they did things, I was the one that they put up on the stand to do the writing and the commentating.*

**Researcher:** *You put it all together.*

**Tom:** *I, I had a great life, I did an awful lot of things, people would never imagine that I got into, I used to be the VIP security officer for the queen and the rest, I did all those sort of things, literally all around the world.*

Tom consistently had a positive way of talking about himself in the past and present. He views himself as having contributed to society and to the couple's relationship in a tangible practical way. I suggest that Tom stabilizes his sense of self in part by voicing this self in the present and recalling a common understanding of who he was with his wife.

In the next excerpt, Tom tries to resolve and bring consistency to his current situation by talking about his current self and those aspects of his situation that are unrecognizable to him. Tom describes his current problem as a "short term memory" and minimizes this as a temporary "hiccup." He becomes aware of this problem during the everyday activity of going to the store when he comes home without the item he was supposed to buy:

**Tom:** *But the bottom line is that I recognize that I've got a very short memory. Now. That's what my hiccup is.*

**Mary:** *So what are the things that you're forgetting then for your memory loss, what, how would you describe?*

**Tom:** *Short-term memory I think.*

**Mary:** *Um-hmm.*

**Tom:** *Because when I stop to think about it and work through it, yes this and that.*

**Researcher:** *Do you have tricks to remind you to remember things like writing lists?*

**Tom:** *Yeah, along those lines but basically getting more used to the idea of writing something down.*

**Researcher:** *So, you're adjusting to that.*

**Tom:** *Yeah, adjusting to that, so that when I come back, geez I forgot that, you know and the minute I come in, bingo.*

In this second excerpt, Tom acknowledges to his wife that he has short term memory. He indicates his understanding of how this is manifested in day to day activity (e.g., sometimes he forgets something from the store). He then affirms his increasing use of coping strategies to deal with these shortcomings. Tom thus makes efforts to reach and protect a shared understanding with his wife. He is indicating to his wife that he remains capable despite difficulties in the current context of dementia. In the third and fourth excerpts, Tom describes difficulty achieving a shared understanding with Mary.

Tom's responses shift within interaction (from the unfamiliar to the familiar). In his narrative, the responses imply an attempt to convince Mary to change her responses so that they can resolve his tension about who he is in the current context of dementia. His short-term memory "hiccups" present a problem for his sense of self continuity and this dissonance may not be completely resolved. Tom nonetheless expresses self continuity in describing his actions. He contributes to the household by going shopping and responsibly compensates for his difficulty by: a) acknowledging it; and b) taking efforts to mitigate it (e.g., writing things down).

An outline of the analysis of Tom and Mary's third excerpt is provided in Appendix 10. In this excerpt, Tom again uses the term "hiccup," this time to describe how he is having difficulty understanding Mary and remaining calm. He goes on to identify another problem – trying to avoid startling or disturbing Mary as his everyday routine changes:

**Tom:** *The biggest hiccup for me is the ability to communicate rationally without getting frustrated and Mary will say something to me and I've not fully understood what she said, so I've asked her a repetition and sometimes I'll hear a word and there's a couple of letters in the word and sometimes I'm a little slow in responding because I'm*

*trying to analyze exactly what it is that she said and, and that creates a lot of frustration, a lot of frustration to the point sometimes I raise my voice a little more than I should and that to me that's not me and but it's hard sometimes for Mary to understand just how difficult it is for me to translate some of the things she said or fully understand where she's coming from. It's sometimes like as if I'm listening to a conversation that's half said but I've understood the first half of it. That, that is, what shall I say, to me it's probably the biggest hiccup.*

**Mary:** *The crux yeah.*

**Tom:** *The frustration is coming up the stairs at 7:00 and putting the kettle on and poor old Mary when she gets startled she explodes.*

**Researcher:** *And you're trying, and you're trying to do your best and you can't seem to avoid that, yeah.*

**Tom:** *Yeah, I can't seem to accommodate, accommodate that, that sneaky trying to get by like a burglar coming in. Yeah. It's, what shall I say, I think the communication with Mary has been the, the moving in the house with Mary being so sensitive to hearing and no matter how hard I try to, to accommodate, it's frustrating and gets a little sometimes and that's both Mary and I am jumping all over the place.*

This interaction highlights the unrecognizable context of dementia for Tom. Mary's behaviour has changed from what he knows it to be. His current self "I can't accommodate or no matter how hard I try to accommodate" is a description of a person who is no longer familiar to him. In this context of dementia, he describes how he is having difficulty making sense of who he is in the relationship; this self is not continuous with how he understood himself to be in relationship with Mary. Tom's response suggests that the solution to his having difficulty would be for Mary to stop behaving in this inconsistent manner. Tom's wife does not respond to him in a way that reinforces how he knows himself in relationship. He acknowledges that he cannot accommodate for how things are now but he is trying. He gives voice to his concerns in the interaction.

A fourth excerpt from the couple exemplifies how efforts toward mutuality include the responses of the unfamiliar self:

**Tom:** *With the interaction right now with Mary and I it's, it's painful and it's frustrating to know how to deal with it. In a nutshell that's, that's it. And that's, that's hard.*



Tom describes himself as having painful emotions and being unsure of what to do to alleviate these painful emotions. His comment suggests that he does not know what to do with the interactions he is having with Mary. He gives voice to the unresolved self to who he knows himself in relationship and to how he knows who he is relationship and consequently how he fits into his current context of dementia. In this interaction with Mary he again gives voice to this unresolved aspect of his current situation.

In summary, Tom's unresolved self expresses how important it is for him for Mary and for others to understand him as more than a person with dementia. He expresses his agency in the narrative by frequently reinforcing and re-emphasizing the positive aspects of his past life with Mary in light of the current context of dementia. Talking about the past in the present helps reinforce Tom's present self understanding in reminding Mary, himself and others that this is still who he is.

### **Paul (PLWD) and Elizabeth (Spouse)**

Paul and Elizabeth had been married 52 years at the time of the interview. Paul was 75, Elizabeth was 72. They had two children both of whom at the time were living in Winnipeg. Their daughter was getting married in the coming summer and they were renovating a cottage so they could live there over longer periods of the year. They both described themselves as healthy. They were both mobile. Paul who has Alzheimer's type dementia also indicated he had back problems. They had lived in a new home for three years. Their home was sparsely decorated. The interactions took place in their living room. I sat on a couch and the couple sat in separate chairs. I had to ask Paul to move closer to me at times to facilitate recording his story.

Like Tom, Paul defines himself as someone able to overcome difficulties, and as someone having difficulty with changes in his interactions with his wife. Paul also reflects on

past difficulties. In the first three excerpts, Paul characterizes himself as someone who overcomes difficulties. In the fourth excerpt, Paul describes himself as angry because of the way things have changed related to his dementia. In this first excerpt, Paul describes how he developed his speaking skills and did not shy away from the challenges of teaching:

**Paul:** *Yeah. And, and so I, I was really really lucky at a very early age and I started off like I got the job at the school, you know here I'm a complete green guy.*

**Researcher:** *Yeah, you had a very important position at the school.*

**Paul:** *Yeah, you know. I had several coaches that reported to me and nobody had reported to me, other than my wife you know (chuckle). (Looks at wife to include her in conversation) So it, it was a real challenge and I had never taught courses you know and I can still remember I was really really you know speaking in front of, it used to really scare me. My last course I took at University of Edmonton was a speech course, you had to graduate but I waited till my last term to take it because but I, I joined Toastmasters.*

Paul can be seen as attempting to reinforce self-continuity in who he knows himself to be within interaction with others. In this second excerpt, Paul describes how he contributed to relationships and how he understood himself to be in relationships:

**Paul:** *Or you know it's, its, it's a distinct thing you know you, why does a stranger, why did the stranger Dave Smith want to see me you know and the big thing is the secretary, to get through to her to get to the guy you want to talk to.... because they're hounded by everybody.*

**Researcher:** *Yes, how do you work your way around it.*

**Paul:** *And so holy mackerel you got to, you got to change what your, your presentation so to speak you know. Yeah, you have to, and I could tell, holy mackerel you know I'm not gaining anything here, I got to change my, my message you know and, and to try and change your message, your initial message to make sense to now what you're doing to come up with something that will keep their interest. But one of the things that I was really lucky that I was a hockey player for seven years and maybe they were a hockey fan, a lot of them were. And then once you got in you got to tell your story. And I could, I could always tell when I was getting through and there was a good chance there were going to get some funding.*

In a third excerpt (from the individual interview), the context of dementia includes Paul's word finding difficulty. He describes how and why this context is difficult for him currently. In

the excerpt Paul is making a link between the difficulty he used to have and the difficulty in overcoming this difficulty like he used to be able to. Paul stated:

**Paul:** *I went to Toastmasters to develop my speaking skills. Lately I was asked to do a speech and I was tempted to do it but I didn't because I've already learned just even talking to Elizabeth at times I can't find the word, you know. And it's real bothersome for me because I, I used to have a stutter.*

In this third excerpt Paul recognizes how current language difficulty occurs in his interaction with his wife. He feels unable to overcome his difficulty. The responses of the unfamiliar self reflect his sense making as an unresolved self in the context of dementia. Paul voices his dismay at being unable to overcome his current challenges with dementia.

A fourth excerpt is selected to highlight Paul's efforts toward mutuality by expressing his difficulty with self in current interactions with Elizabeth. He describes his response to an unrecognizable context of dementia when Elizabeth does not answer the questions he asks her. Paul describes his unfamiliar response to Elizabeth (and me) as an unresolvable self:

**Paul:** *So I had never shared that with her. Yeah, I would say that's, that's my, my biggest challenge right now or you know and I, and I'm the one to blame.*

**Elizabeth:** *It's not that you're, Paul you're not to blame.*

**Paul:** *But I can't accept when I ask my question, when I'm asking a question or for help and it doesn't happen often, but it happens enough, she denies it or she won't tell me and that, that really, really bothers me. It won't go away. It gets me angry.*

Paul's responses are of the unfamiliar self in this last excerpt. This articulation of his difficulty is similar to Tom's. He attends to the relationship with his wife by bringing up the difficulty and by suggesting that Elizabeth's responses to him need to change. Paul's responses in the narrative reflect an effort to re-establish continuity in the way how he knows himself and the way he is in relationship with Elizabeth. In this interaction his expression of his unresolved self is an expression of his agency to attempt to change relationship in his current context of

dementia. In summary, as evident in these excerpts, Paul seeks to establish who he was in the past, and to interpret past situations and their meaning in the current context of dementia.

### **Evelyn (PLWD) and John (Spouse)**

Evelyn and John had been married for 50 years. They had been living in an assisted living arrangement for 10 years. John was legally blind. They were both mobile though John used a cane when walking outside the home. They had two children who both lived in Winnipeg. Evelyn had been diagnosed with dementia about two years prior to the interview. Evelyn and John both spoke about Evelyn's dementia. The interview was conducted both at their kitchen table and in their living room. In the living room, I sat on the couch and Evelyn and John sat on different chairs.

Like Paul, Evelyn describes experiences and roles of her past as contributing to self-continuity. Evelyn's ability to recall this past in current circumstances reinforces her sense of self in relation to others. In the next four excerpts, two illustrate the significance of Evelyn's past role as a nurse to who she is now and how she has related to others including her husband. In the last two excerpts she may be resolving the inconsistencies she is experiencing in the context of dementia.

In this first excerpt, Evelyn shows agency because she seems to be saying what I was in the past I can still remember, so it is still an aspect of who I am:

***Evelyn:** Well I have my LPN training. And I always say those were the best years of my life, my nursing...*

Evelyn's positive recall of her past nursing experience in the present expresses a response of the familiar self. Recalling the activities and roles of the past reinforces who she is now as this part of her continues. This in turn facilitates her shared understanding with her husband (John) in her current context of dementia. The following interaction occurred during the novel

activity of photo-elicitation. The couple was looking at and responding to a photograph I had taken of a hospital where Evelyn had worked in Newfoundland:

- Researcher:** *This is a picture of?*  
**Evelyn:** *[Location]*  
**John:** *Yeah, she had very good relationships there.*  
**Evelyn:** *Good experience, nursing experience.*

In this excerpt, Evelyn's positive recollection reinforces who she is now because of these relationships in the past. Evelyn's responses of the familiar self are attending to the significance of her past nursing career. John also reinforces this significant aspect of her past.

Evelyn's current self, however, in the context of dementia is an unfamiliar self as described in the excerpt below (see Appendix 10 for outline of analysis):

- Researcher:** *What kind of changes have you noticed in your life in the last couple of year? (directing question towards Evelyn)*  
**Evelyn:** *In my life?*  
**Researcher:** *Yeah.*  
**Evelyn:** *Well interest levels are dropping.*  
**Researcher:** *Yeah.*  
**Evelyn:** *No, it's not pleasant. (Evelyn starts crying)*  
**Researcher:** *Yeah, you look like you're feeling really sad, feeling sad yeah. There's been a lot of changes that have been hard for you.*  
**Evelyn:** *Well yeah (long pause) you feel sort of alone*

Difficulty occurred within the interview when John tried to explain their interactional struggles:

- John:** *And I thought we knew all about it. And that morning we went to church I mean Evelyn and I did and after church we went out to meet with Jacob and I hadn't realized that that was all gone, and when we got to the other church she didn't know "where have we gone", "where are you taking me." That was completely gone. And so now I realize that I need to check more often, but when I do check...she says "why are you checking, and we talked about that."*  
**Researcher:** *Okay. Yeah, its like how do you know what to do?*  
**John:** *So it's this kind of struggle that we're having there now and that's where, then you wonder should you be talking about it or not and yet if I don't that doesn't, that isn't right either. But and when we're talking about our daughter...*

**Evelyn:** *Okay, but this is what is happening right now, it hasn't happened that way all our life. (Evelyn crying)*

**Researcher:** *Right.*

**John:** *No, it hasn't. And this is where it's hard for both of us to adjust.*

**Researcher:** *It has been a struggle for you. (talking to Evelyn)*

**Evelyn:** *And it has been.*

Evelyn expresses her awareness of her own current, unfamiliar behaviour. By asserting “things have not always been this way” in response to John’s description of her behaviour she reasserts her familiar self (continuity). She seeks a shared understanding with her husband that acknowledges who she was in the past (i.e., without dementia). She articulates how she wants to be understood in her current interaction.

In sum, the interactions between John and Evelyn show Evelyn trying to make sense of her current circumstances. Her responses highlight the significance of her past roles and her experience of shared understanding with her husband in the present. Unresolved aspects of her current interactions contribute to a lack of shared understanding. Evelyn’s responses are similar to Paul’s and Tom’s: they give voice to their sense making process. Tom, Paul and Evelyn express their agency by reinforcing who they were in the past with themselves, their spouse (as well as the researcher) to foster their understanding of self.

### **Sam (PLWD) and Roberta (Spouse)**

Sam and Roberta had been married 49 years and had been living in their home for 30 years. Sam was 74, Roberta was 70. They had two children. One lived just outside of Winnipeg. They both described themselves as healthy. They were both mobile and able to walk long distances. Sam had been diagnosed with dementia four years prior to the interview. Their home was very tidy and well organized. Most of the interactions took place at their kitchen table. They had a dog that would occasionally become part of the interview.

Like Evelyn, during Sam's interactions with his wife and others, he becomes aware of how his dementia interrupts his sense of self in relation to others. Four excerpts illustrate his expression of his sense making process. In the first two excerpts he describes his past experiences. Like Tom, Paul and Evelyn, he describes his continuity of self in relation to a past positive career and accomplishments. In the last two excerpts, Sam identifies difficulties with himself, including gaps in his ability to communicate. Sam describes strategies to overcome his difficulties and in doing so maintains self-continuity. In the first excerpt, Sam recollects events that transpired prior to receiving his first teaching job:

**Sam:** *Anyway, he came up to me and he said sit down, sit down Mr. "S". And I sat down and he said, I'm a guidance counsellor at George Hammer High School. We're starting open area, team teaching, individualization of instruction, he said what I saw happen today is the very thing we need at our school. You're flexible, you're adaptable and you have a presence (chuckle). And you know would you be interested in coming for your last section of practice teaching at George Hammer, so we can really evaluate you, there could be a job.*

**Researcher:** *Um-hmm, um-hmm.*

**Sam:** *Yes (chuckle).*

**Researcher:** *Yeah.*

**Sam:** *And I worked there for 30 years (chuckle).*

Sam is recalling a past event in which his positive qualities as a teacher were recognized and rewarded. He is having responses of the familiar self. He highlights his career consistency (30 years), which emphasizes his dedication and perseverance. Recalling these aspects of himself is comforting for Sam as he connects his past identity to his present situation. It is also possible that Sam's talk of himself as a long term teacher has parallels to the contribution he makes to his long term relationship with his wife. In this way his narrative has the potential to reinforce who he is in relation to her (and may facilitate shared understanding).

Other positive narratives of Sam's career as a teacher are included in a second excerpt:

**Sam:** *I was actually glad I was a junior/senior high [teacher] 'cause I think you learned a lot from junior high kids that you wouldn't pick up from senior high kids, they're just at a different stage of life, both, both groups and so.*

**Researcher:** *Yes*

**Sam:** *Yeah, you had to find little tricks that would be better than grinding your teeth (chuckle) when you were dealing with a situation.*

**Researcher:** *Yes.*

**Sam:** *But a lot of it was just pure joy.*

Similar to Paul, Sam describes in this excerpt how he overcame difficulties. He made the best of sometimes difficult situations by understanding the nature of the problem (e.g., “they’re just at a different stage of life”) and by enjoying those aspects of the situation that he could. In talking about himself in this positive manner, Sam shares his current understanding of how he knows himself to be in the interaction. This sharing is with his wife. The telling reinforces who he is and is his attempt at convincing others, especially his wife, that this is a part of who he remains.

In a third excerpt, Sam describes his current challenges as ‘gaps’ that he tries to manage in ways that mitigate the impact of his condition on others with whom he is in relationship:

**Sam:** *Yeah, I need, I need cues more than I ever had.*

**Researcher:** *And but you remember to look at lists or do you...*

**Sam:** *Well I've got this day timer here and Roberta will use the whiteboard to help me and you know tell, tell me when she's around directly. And so that's, that's basically the way it is. And the way I deal with everybody now is I remind them or tell them right away when I'm meeting them that I do have Alzheimer's and that's, and that's purely defensive on my part to let them know if I should see them again and don't recognize them or can't recall what we were dealing with or recall their names which is more likely to happen, that it's not a matter of snubbing them or not valuing you know whatever interactions we might have had but the fact that I have Alzheimer's, there are gaps now that, that don't allow me to remember some of these things anymore. And in a way it's a bit of a copout 'cause it takes me off the hook in my mind at least (chuckle) and but I think it's, I think it's a little kinder to other people too, just in case they do think I'm not valuing them, or never did value them because why don't you remember me, we did this together.*



Sam describes his responses to his dementia as “purely defensive” strategies that not only consider and take into account the other, but also help him feel better personally. Ultimately, however, Sam’s effort to ensure people understand his situation helps connect him to others. Sam’s description of wanting to be kind to others is consistent with his sense of self. This again exemplifies Sam’s response of the familiar self. He is able to bring a sense of continuity of self. Who he is now is continuous with who he was then. The responses of the familiar self convey how Sam attends to others as he always done.

The final and most notable excerpt is one in which Sam expresses his experience of self in the context of dementia:

**Researcher:** *Yeah, Can we go back to talk about your experiences teaching Tai Chi?*

**Sam:** *Yeah.*

**Researcher:** *So, when you realized that people were having difficulty following what you were saying when you were instructing them in Tai Chi, what did you do?*

**Sam:** *What I did then is I, I just, I just resigned as an instructor. I just said you know I’m, I’m, I realize that I’m having gaps now. And you know I don’t want to be misrepresenting the society.*

Sam had previously described the events that led to him quitting Tai-Chi instruction. He came to realize he was not connecting with people during instruction; the way people were responding to him informed him that he was having gaps. Sam’s response was consistent with his sense of familiar self (that he values others and organizations) and his decision to stop the Tai Chi activity conveyed a dignified and respectful response.

### **Harold (PLWD) and Alice (Spouse)**

Harold and Alice have been married for 21 years. It is the second marriage for both. Harold and Alice married after both of them retired. Harold was 80, Alice was 78. They have lived in a condominium for 10 years. Alice was a single parent of three children most of her working life. They had a dog the first two times I saw them but the dog died between my field

visits. Harold had no children from his first marriage. He had been diagnosed with a vascular type dementia 10 years earlier. Two years ago Harold was diagnosed with Lewy Body Type dementia. This type of dementia is associated with more mobility problems and more hallucinations as compared with Alzheimer or vascular type dementia. Harold also had medical problems related to his heart and was on medication for this. Harold was in a wheelchair during a few visits but was able to transfer independently and walk short distances. Alice did not describe any health or functional problems. She was active. None of her children lived in Winnipeg, two of them lived outside of Winnipeg and another in the United States. One of her children had recently been diagnosed with Multiple Sclerosis which was a significant stressor at the time of the interview. The activities and interviews were conducted at the kitchen table and in the living room. The seating arrangements altered in the course of interviewing this couple.

Harold does not use the same sense making process to sort out how he fits into his social situation as Tom, Evelyn, Paul or Sam. Three excerpts are intended to exemplify how Harold expresses his sense making in the interaction. Harold's narration included little sense of the familiar self in the past; however, Harold was comfortable and familiar when he was conversing in the present. He followed conversation, contributed novel comments, and described Alice positively. In these excerpts, Harold expresses continuity by referring to those aspects of his current situation that are comfortable and familiar. In one excerpt, Alice is describing qualities of Harold that identify his difficulties. He seems to divert attention away from this topic by describing his interest in books:

**Alice:** *But he doesn't find things in the cupboard, he can't find things in the fridge.*

**Researcher:** *And that's most notable in since you've moved here and getting worse.*

**Alice:** *Well very definitely, yeah.*

**Researcher:** *Um-hmm.*

**Harold:** *My big achievement. I sort of tailed off reading books.*

**Alice:** *Oh yeah.*

**Harold:** *And I, I'd started several books in the last year and never finished them. I started reading a Grisham book.*

**Researcher:** *Oh yeah.*

**Harold:** *On the boat and read five more by the first week in February. And a book called *The Gold Castle*.*

**Alice:** *Okay.*

**Harold:** *Which "Alice" found a fascinating book, it's a woman who wrote the .....*

Harold's comments are a response to Alice's description of his memory deficits.

Although he appears to be identifying another deficit (not finishing books), his narrative nonetheless redirects the focus of interaction to an activity that he and Alice share (e.g., moving towards a point of shared understanding, in particular their having read a certain book in common). Harold's responses are the familiar self. He is attending to his relationship with Alice in his description of self and what he has in common with Alice.

In some ways, Harold positions his current difficulties as compatible from past difficulties as suggested in the following excerpt:

**Researcher:** *So, so how, how long would you say that you have had memory problems.*

**Harold:** *All my life. I had a hell of a time in school from my start at 27 till when I quit when I was 35, I always had memory problems.*

**Researcher:** *Memory was never your best asset.*

**Harold:** *No, I, I couldn't recall stuff. I probably wasn't a very good studier but I just couldn't, never did.*

**Researcher:** *Yeah, that's what I think too. So, is there, is there anything else that affects you, like affects your memory or affects your thinking or?*

**Harold:** *I guess the dementia probably. I, I was a long time drinker too and I've been sober since '81. So I'm sure that it had some affect some time or other, whether it was the carryon affect after I sobered up, I never pursued looking or trying to find that out.*

**Researcher:** *So you, you felt that you drank a lot and at some point or another and that might have affected your brain.*

**Harold:** *Yeah, I drank a lot, I was a qualified alcoholic.*

It may be that Harold actively reinforces a sense of continuity by highlighting the consistency of memory problem between his past to his current situation (and indeed, trying to

connect them causally). Harold makes sense of himself and his current circumstances of having memory problems as a stable part of who he knows himself to be.

In a third excerpt, Alice and Harold talk about relational stories while I take photographs of them. This excerpt is a part of a description of Alice and Harold's marriage (a second marriage for them both). They had dated each other as older teenagers, had gone their separate ways and then met again later in life. It is within the interactions with his wife, and their process of shared story-telling, that Harold expresses the continuity of his self-in-relationship with his wife:

***Alice:** He just sort of fit right into the scene it seemed like, the kids enjoyed him and mind you they were all older teenagers and early twenties by then but anyway. And of course all my relatives remembered him because he had been around for so many family occasions during our high school years. So, everybody knew "Harold" and remembered him.*

***Researcher:** Hmm. So then, so getting married wasn't a hard decision.*

***Harold:** 40 years (chuckle).*

***Researcher:** What's that?*

***Harold:** I said I'd been waiting for 40 years (chuckle).*

***Alice:** (Chuckle)*

Harold's responses, and the telling of this story about the past in the present, serve the purpose of reinforcing his commitment and devotion to his wife and thus his self-continuity.

In summary, although Harold does not speak positively of himself in the past, his responses suggest a sense making of who he is in relationship by directing attention to those facets of his current context that highlight maintaining a shared understanding with Alice. Their interactions draw attention to the significance of shared story telling of past events as a means of maintaining mutuality.

### **Peter (PLWD) and Ruth (Spouse)**

Peter and Ruth have been married for 59 years and have 4 children together. All four children live in Winnipeg. Peter was 80, Ruth was 76. Neither Peter nor Ruth talked about Peter

having dementia in the interaction. Peter made several references to the difficulty he had with his memory. In one of the interviews Ruth described that her husband had been put on a medication to help him with his memory. They had lived in the home they currently resided for the length of their marriage. Their home was situated on a busy street near a school. The home was very full of crafts and craft material. Cabinets were full of dishes, bookshelves were crowded with books. They had two pets. These pets configured significantly in the field visits. The dog often barked and Peter told the dog not to bark. Ruth described herself as active and healthy. They were both independently mobile. During field visits the phone rang frequently. Ruth was arranging appointments, dinners with their children and setting up days when she would be selling her crafts. When asked in the initial questions if there were any changes in their life that were significant, neither responded by talking about dementia or memory changes. The interviews were conducted in the kitchen and in the living room of their home.

Peter is further along the dementia journey than Tom, Paul, Evelyn, Sam or Harold. Peter's responses suggest a sense of continuity of self not always well articulated in the interaction. This sense of continuity occurs in how he experiences his shared common understanding and environment with his wife. Peter appeared most comfortable and his abilities were most evident in interaction with his wife.

Peter expresses a sense of self that is unresolved, his unfamiliar self when the interaction reminded him that he has difficulty remembering. The following comment by Peter is a response of the unfamiliar self. It was made in his individual interview, when asked what he used to do for a living: *"I, my mind is, isn't what it used to be. Yeah, I know I did something with pipes but I can't remember what. That's terrible."* He recognizes that not being able to remember in the interaction reduces the shared understanding between himself and the other he is speaking to. In

interactions with Ruth, Peter is not reminded of difficulty remembering and articulates how he still values being in relationship with others. Peter's continuity of how he understands himself in relationship is illustrated within the interaction; in other words it occurs as he responds in the immediacy of the interactions.

The next two excerpts between Peter and Ruth illustrate Peter's continuity of self expressed within interaction. In the first excerpt, (outline of analysis in Appendix 10) Peter's responses indicate his recognition of the past and its connection to the present. Ruth talks about how she and Peter are going to move into a home built beside her daughter:

**Ruth:** *Yeah. Yeah, she said we looked after her and helped her when she needed help so she's going to help me with dad now.*

**Researcher:** *Oh is that ever nice.*

**Peter:** *Payback time I guess.*

**Ruth:** *(Chuckle)*

**Peter:** *Well I, I enjoyed the kids you know.*

**Ruth:** *Well we, we just about raised her daughter so (chuckle)*

**Researcher:** *Oh yeah.*

**Peter:** *Yeah, I enjoyed the kids.*

This excerpt is meant to illustrate that Peter is a response of the familiar self. He expresses his emotional connection with his family.

In a final excerpt, Peter's ability to interact facilitates a shared understanding in the engagement of having coffee together:

**Peter:** *Thank you. You got milk there dear?*

**Researcher:** *You remember you take milk in your coffee.*

**Peter:** *Yeah*

**Ruth:** *(Chuckle)*

**Peter:** *(Chuckle) Yeah, that I don't forget.*

In this excerpt Peter finds comfort and connection in the familiarity of the activity and his surroundings. Peter's engagement in the social interaction of having coffee offers the opportunity for continuity of the relational self.

In summary, Peter's interactions with his wife, including everyday activities, provide insight into the expression of the sense making of self as 'how I know who I am in relationship.' Peter's recognition of his memory loss shapes his efforts toward mutuality. When he recognizes his loss within the interaction, it is "horrible." He recognizes how the memory loss is decreasing his ability to have shared understanding with others. Peter's narrative also illustrates how the impact of memory loss varies within the specific situational context. The immediacy of a recognizable social situation (having coffee) connects Peter. His responses are these of the familiar self. He knows who he is in this situation and how to relate to others.

### **Emmanuel (PLWD) and Karen (Spouse)**

Emmanuel and Karen had been married for 45 years. Karen was 72. Emmanuel was 79. This was the second marriage for both. They had six children between them. They received a lot of support from one daughter who lived in Winnipeg. They were both mobile and other than Emmanuel's dementia did not speak about other health-related problems. Karen spoke about Emmanuel having dementia. Even though Emmanuel was only officially diagnosed three years prior to the interview, he and Karen were far along in their dementia journey. Emmanuel had been experiencing problems with work for some time prior to the diagnosis. They were living in a large condominium where they had lived for the past 12 years. Interviews and activities took place in the living room. I sat in one couch and the couple sat in another couch.

Like Peter, Emmanuel expresses continuity of self in his responses in interactions with his wife. Emmanuel's connection with his past, his family and his wife are recognizable to him. He has responses of the familiar self. He is comforted and connected within interaction with his wife and when recollecting family:

**Researcher:** *So I'll ask you both this question. Do you have any children?*

**Emmanuel:** *Yes, I do. Several. Yeah. It's been a gift, a beautiful gift. And we have been blessed with the opportunity to have enjoyed the children and, and we have much to be grateful for these children. We have eight children.*

**Karen:** *Eight children?*

**Emmanuel:** *Eight.*

**Karen:** *Eight grandchildren.*

**Emmanuel:** *Eight grandchildren, I'm sorry (chuckle).*

In the process of making sense of their lives, the PLWD strives to reconcile the context of dementia and maintain continuity of self in relationship. They make an effort towards mutuality with their spouses by voicing who they were and who they are. Tom, Paul, Sam and Evelyn revealed continued ability to recall who they were in the past in their relationships. Responses of the familiar self reflecting positive past self create a sense of continuity in the present. They are sharing a way of knowing themselves that they understood was a part of who they were in relationship with their spouses. Harold, Paul, and Emmanuel demonstrated within their joint interviews their sense of self. Responses to their wives conveyed their engagement and interest in shared understanding. This was the case even for Harold, who at the narrative level, responds to his wife by describing what they have in common. Responses of the PLWD also reveal how they have difficulty sorting out how they fit. In the interaction they show agency by making efforts toward mutuality by describing their difficulty, suggesting that it is in the interaction with their spouse that they make sense of how self is now and how they are in relationship.

### **Shifting Responses to Changes in Everyday Activity**

The responses of the unfamiliar and familiar self of each spouse convey their attention to the other while the couples discuss their changed and current everyday activity. Everyday activity is the fulcrum in which each spouse takes notice and attends to the other. There are a number of socially mediated aspects of the couples' context other than dementia that shape the extent to which changes in dementia impact the couples' situation. Most prominently are the



increased home related tasks that a few of the wife spouses pronounce increase their task load in the context of dementia. Noticing how the spouse without dementia and the PLWD respond to the other as they discuss everyday activities provides insight into how dementia is shaping their response. Increased task loads as well as other responses are integrated into understanding how dementia shapes the responses of the couple.

### **Emmanuel and Karen**

Emmanuel and Karen were receiving daily visits from homecare workers to assist Emmanuel with his daily needs. Receiving homecare services signified the many changes in the life of this couple related to dementia, and symbolized how ‘far along’ Emmanuel and Karen were in their dementia journey. At the time of the interview, homecare workers were coming twice a day to assist Emmanuel with dressing, bathing and managing incontinence. Generally, Emmanuel responds to the conversing (back and forth) and specific prompting within the interaction. The following excerpt is from an interaction in which Karen describes changes that have occurred in the couple’s everyday activities.

**Karen:** *But fortunately, we had a wonderful caseworker and he just got us going. He said you can have this, this, this and this and it didn’t cost anything, that’s the amazing, we’ve got a wonderful, I mean sure we have times when they forget, or they change the people and so on. But we’ve, we’ve had very, what, what, don’t you think that the people that come to help us at night and in the morning, haven’t they been very good?*

**Emmanuel:** *Yes.*

**Karen:** *It has involved starting with a Tuesday respite for me and, and then he started in summer, last summer he started a day program at Lion’s Manor.*

This interaction between Karen and Emmanuel illustrates how the couple is attending to each other in their context of dementia. The context of dementia includes integrating homecare services into their everyday experiences. Homecare attendants are now coming into the couple’s home to assist Emmanuel with activities of daily living and Emmanuel is leaving the home to attend a day program. Within the interaction, Karen actively engages her husband with nonverbal

glances and verbal behaviour that convey her interest in his engagement. Though Karen includes Emmanuel, Emmanuel's minimal verbal responses may reflect difficulty in recollection or language retrieval associated with dementia symptoms. Karen does not fully include Emmanuel. She excludes him when she refers to him in the third person. This exclusion could signify Karen's reluctance to draw attention to Emmanuel's cognitive and functional decline. Karen's responses are her familiar self. She welcomes homecare services and strives to achieve positive engagement with her husband about the experience. Homecare in itself is positive for Karen perhaps because it decreases the amount of time that she and Emmanuel are engaged in care activity, the work that emphasizes the declines associated with dementia.

Emmanuel's response indicates some engagement in the interaction itself; he follows Karen's lead by agreeing with her when she brings him into the conversation with verbal and nonverbal cues. Karen's response of primarily the familiar self in the interaction suggests how she has adjusted to the changes in everyday activities. The discussion of changes in everyday activity that now involve homecare services identifies Karen's efforts toward mutuality. Attention to Karen and Emmanuel responses leads to recognizing how each spouse is attending to the other in their context of dementia.

### **Tom and Mary**

Tom and Mary have not experienced the significant changes in everyday activities that have occurred with Emmanuel and Karen, and Tom's symptoms seem less pronounced in interactions. Tom is able to engage in conversation and frequently will come up with novel comments that appropriately contribute to the topic of conversation. Tom is able to initiate new topics that are of particular concern to him. Nevertheless, everyday activities are still an important site of maintaining shared understanding in excerpts from this couple, especially as

Mary's primary response is an increased vigilance to discern the meaning of dementia for their everyday activities. Two excerpts exemplify how descriptions of the everyday activity of exercising and grocery shopping are connected to shared understanding. In the first excerpt the couple describes their everyday exercise:

**Tom:** *Well both of us work out, we have a rowing machine down in the gym and I'm down there anywhere from 20 minutes to half an hour a day.*

**Mary:** *One thing that Tom and I both agree on is we love to exercise, we keep ourselves fit and I really think this has helped him in his journey along the way.*

Doing exercise connects the couple in that they both describe the activity as something "we" do together. For Tom, exercising is something that he and his wife have in common that connects his past self with his current self. However, Mary switches her description of exercise from something 'we do' together to a journey that Tom is on by himself, essentially distancing herself from her husband and characterizing his own exercise as more instrumental or therapeutic compared to her own (which is positioned more strongly as enjoyment).

In another excerpt, Tom and Mary discuss grocery shopping; their interaction exemplifies Mary's watchfulness. As with the previous excerpt, Mary describes Tom's ongoing abilities in a manner that suggests her attentiveness to the possibility of change (or at least helpful intervention). In this excerpt, I asked whether grocery shopping changed in the last while:

**Mary:** *No, no, Tom's quite okay to go on short trips, he wouldn't go if it was somewhere that he didn't know. He goes shopping, he loves to shop, grocery shop, and we use the cell phone a lot when doing that.*

**Tom:** *Mary doesn't like shopping so I go out under supervision.*

**Mary:** *Yeah.*

**Tom:** *(Chuckle)*

**Mary:** *He goes; he goes loaded with a list and I stay at home.*

**Tom:** *And I say that with tongue in cheek.*

**Mary:** *And then of course he'll phone to say, was it this brand you wanted or that brand, he's very good at that and he's become a very good shopper actually. Yes, he is. And anything he does he's super really.*

*Tom: I'll show you as a result of being brought up on a farm I learned that things got to get done, and you made it happen individually. It has stuck with me and in the life I have had in the army.....*

In the interaction, Mary indicates that grocery shopping has not changed significantly and it is unclear whether or not Tom shopped with supervision prior to his diagnosis of dementia. Mary's description suggests that their current context of dementia continues to mean that each spouse makes a contribution leads to the successful accomplishment of grocery shopping. Grocery shopping includes a short trip for Tom, Mary makes the list, and Tom selects the items and phones Mary if he is unsure. Both Tom and Mary are relating in a manner that is continuous with how they know themselves in relationship. They are both having responses of their familiar selves. Tom engages in humourful banter in response to Mary's positive comments about his capabilities. Tom also makes a positive comment about how his engagement in grocery shopping connects to his value of getting done what needs to be done; and to whom he was in the past.

Tom and Mary have shared understanding about grocery shopping. As in the first excerpt, Mary's responses reflect an underlying concern about possible changes as they are reflected in Tom's activities and a desire to understand how these changes will shape their shared understanding. It is within the larger context of her and Tom's life together that Mary interprets everyday activities. The dementia diagnosis and changes in Tom's ability appears to shape her descriptions of everyday activities. Reinforcing the continuity of everyday activities may re-establish the mutuality of the couple, particularly for Mary.

The previous couples (Emmanuel and Karen; Tom and Mary) exemplify two different dementia contexts but their excerpts illustrate how changes in everyday activities may initiate a new (but still shared) understanding of what it is to be in relationship with the other. The next

two couples (Alice and Harold; Elizabeth and Paul) exemplify how changes in the everyday activity manifest as distancing in shared understanding.

### **Harold and Alice**

Alice's response to everyday activities accentuates how the spouse's experience of these changes can suggest difficulty in shared understanding between the couple. Two excerpts exemplify how talk about everyday activities conveys their difficulty in shared understanding (distancing). In the first excerpt, Alice responds to a question about everyday activities of the couple by emphasizing her own work:

***Alice:** I do all the care work; that is I look after the car, I look after the banking, I look after appointments. Harold sometimes will phone and make his own appointments, but I make sure he gets there.*

***Harold:** Yeah.*

***Alice:** I do the shopping, carry out the garbage.*

Though it is not explicit in this interaction, Alice's response implies the number of activities she is responsible for has increased. Alice's response suggests that her increased task load is related to a previous role with her husband in which she held most of the responsibility of household chores. Alice has to 'take over' much of the activity either because of Harold's dementia or his physical difficulties. Whereas Tom and Mary express a shared understanding about grocery shopping, Alice expresses a sense of distance in their activities (e.g., through the division of labour); Harold appears to agree (suggesting an effort to engage towards shared understanding), yet ultimately, there is little sense in this interaction that the couple shares a positive sense of moving forward together in a mutual journey. What is most significant in this interaction is Alice's responses in the joint interview are not attending to her husband's response. This is a response of the unfamiliar self of Alice. Alice does not engage Harold in her responses

and refers to him in third person. Understanding the interactional consequences of increasing task load provides insight on the consequences of dementia on shaping mutuality.

In a second excerpt, the couple responds to a question about activities in which they currently engage together:

**Alice:** *We don't go to movies because Harold doesn't care for movies, I love movies, but I want somebody to enjoy it with me so I don't go anymore. What do we...*

**Harold:** *TV though.*

**Alice:** *Yeah, we watch some TV together while you're awake.*

The couple has difficulty coming to a shared understanding about whether any current activity is indeed shared. Harold seeks agreement and a common understanding in suggesting that they watch TV together. Alice's response is double-edged. Although she agrees they do watch TV together, she qualifies this by adding "while you're awake," reinforcing a sense of separation (i.e., that the activity is not really shared). Although Alice expresses continuity of self by describing her interest in going to movies in the past, this only serves to reinforce and emphasize her disappointment with not going to movies currently. However, both Harold and Alice engage in the topic together and respond to what each other say. Though there is little common understanding found in the topic of conversation, the engagement in the discussion indicates each other's interest in identifying a shared activity.

Harold's response to Alice's descriptions of everyday activity identifies his agency or the action he takes within the interaction to foster his relationship with Alice. Alice diminishes the significance of this activity in her response to him. In this, she may be expressing her unmet needs in the current context of dementia. The specifics of the context of dementia are not clearly expressed in the interaction between Alice and Harold. Unlike Mary, it is not clear that Alice is responding to the symptoms or perceived symptoms of dementia in the interaction. As each spouse attends to the other within the context of dementia, their responses engage their personal

and relational history. Responses suggest how the context of dementia is complex and multifaceted. Distinguishing each couple's responses highlights opportunities for acknowledging and appraising this complexity.

### **Paul and Elizabeth**

In the following excerpt, Elizabeth like Alice, lists the activities she must do. Like Alice, Elizabeth's description suggests she is inundated with everyday tasks that she must accomplish:

**Elizabeth:** *And I have to say at the moment the life is pretty hectic between Paul, a wedding, a cottage that we're trying to build and then our daughter is going to live out of town and so Paul would like to move into our daughter's house and sell this house, so that would mean packing everything up and moving. Well that's a pretty heavy, heavy load to carry.*

**Researcher:** *Yes, huge.*

**Elizabeth:** *And so it's, it, it just, sometimes it's, and then for Paul to do anything and he loves to socialize and he loves to chat with people. Much more so than I. But then it's, you take him there and you take him back and it's very time-consuming and then you add in doctor's appointments, it's hard to accomplish. And I like to accomplish in my life, so it's hard not having that sense of accomplishment, you're more just sort of drifting from one thing to the other to the other to the other.*

**Paul:** *And just to add a point, we did, we did our teaching degree in Ohio*

There is a suggested difficulty in shared understanding in Elizabeth's description of all the things for which she is now responsible. Paul's response redirects the topic to what he perceives was a shared activity and understanding between him and Elizabeth in the past. Paul has some difficulty with word-finding and his memory, but can follow the conversation and contribute novel comments.

Elizabeth's description of everyday activities, and their different personality traits, distances her from Paul. A lack of shared understanding is reflected in Elizabeth's reference to Paul in the third person and by excluding him in the conversation. It is also expressed in how each partner reviews their current circumstances. Elizabeth was "accomplished" and now she is "having difficulty accomplishing," for instance. Similar to the analysis of the interaction between

Harold and Alice, Elizabeth's increased task load is related to Elizabeth having had a primary role in which she balanced household activities with other roles. She is left now with increased task load within this context of dementia. Her responses of the unfamiliar self reflect this changing context. Paul, however, attempts to redirect the conversation to those aspects of their life together that they do have in common. In both of their responses Elizabeth and Paul are expressing an effort toward mutuality. Similar to Harold, Paul's responses identify his agency to contribute to creating a new mutuality between the couple in the face of changing everyday activities.

### **Evelyn and John**

The next excerpts from interactions between John and Evelyn further exemplify the process of coming to a shared understanding about the meaning of changes in everyday activities. Evelyn and John were sitting beside each other in the first interview but there was not much joint interaction. The couple responded to each other through their interaction with me, that is, either John or Evelyn would speak to me, but not as frequently with each other. Despite this way of interacting, the bond the couple was evident. Aspects of their interaction that conveyed their bond were the frequent references to 'we' and the sadness that each expressed with the changes occurring in their life together. John was especially careful to compliment Evelyn and did not seek retribution in the interaction when she described him as difficult. In the first excerpt, it is clear that Evelyn's memory and her ability to attend to activities has declined. However, she continues to be able to engage in interaction and conversation. John describes how going to church was an activity they did that has now changed and is no longer recognizable, illustrating difficulties the couple faces responding to the context of dementia:

**John:** *And with the dementia that we're working with it's harder to be able to sort that out. We could do more before but now we're not able to do anymore. And*



*what's happening now is trying to get up in the morning to go to church when you don't have that attraction that you had before.*

**Researcher:** *Yeah,*

**John:** *Okay you're getting the picture there.*

**Researcher:** *Uh-huh*

**John:** *And that is not easy, but then she feels very uncomfortable about it. And then one morning when I came home from church and she was still in bed. She was upset with me that I hadn't made her get up in the morning because she had wanted to go.*

**Researcher:** *Oh.*

**John:** *Yeah but it doesn't work if I try to make her.*

Going to church was an activity that both he and Evelyn shared when she was not working weekends as a nurse. Recently, Evelyn has been less inclined to want to wake up to attend church, yet she is also upset when she realizes she has missed church (she does not remember telling John that she did not want to go).

John's responses reflect an interpretive process of trying to understand how dementia is shaping their current shared understanding and shared activities: "We could do more before but now we're not able to do anymore." Moreover, both here and in other comments, John uses the phrase "we," which implies that he and Evelyn are in this together (e.g., "with the dementia that we're working with"). In discussing the activity as 'we,' John's response suggests that how he knows who he is and is connected to his relationship. When John uses the term 'we' he connects himself to Evelyn in the current interaction and it is suggested that this is his efforts toward mutuality.

Though John often speaks as if Evelyn were not present and tends to dominate the joint interview (doing most of the talking), slightly later in the interview Evelyn demonstrates her own agency to reinforce her continuity of self within interaction. In this interaction, Evelyn is the one who responds to my question. The impression I had at this point of the interview (captured in

field notes) is that Evelyn's response was related to some of John's previous comments in the interview about her behaviour.

**Researcher:** *So I want, I want you to think of an activity that you both agree that you do together. What's an activity that you do together, you like to go walking.*

**Evelyn:** *I like to go walking but I'm a loner, I like to go by myself.*

**Researcher:** *Is there anything you like to do together.*

**Evelyn:** *Hmm?*

**Researcher:** *Is there anything you like to do together, you and your husband?*

**Evelyn:** *Well we do things together, but we are different. You know very much.*

**Researcher:** *Yeah. That's the way it should be.*

**Evelyn:** *Our families and everything it has been a difficult adjustment and I don't know if I've adjusted wholeheartedly.*

**Researcher:** *Yeah.*

**Evelyn:** *No, it's...*

Evelyn raises the activity of walking in a way of distancing herself from her husband. She likes to walk, but she prefers to walk alone. She highlights how she and her husband are different. These descriptions of herself as a loner, as having difficulty adjusting, as being different from her husband convey her awareness of the lack of shared understanding with her husband. However, Evelyn expresses her agency when she gives voice to herself and emphasizes her continuity of self. Evelyn's description of self in the interaction expresses her relational self; that self that needs to make sense of self through a sense of continuity of self. Her continued ability to articulate who she is or voice who she understands herself to be in relationship may facilitate her ongoing connection in interaction.

#### Summary of Chapter 4

Answering research question 1 involves describing how the intimate couples responds in the interactions when each couple is talking about everyday activities, their relational stories, when they are having coffee together and with me, when they are having their photograph taken and when they are making a decision about which is the best photograph. Responses are

observable behaviours that are interpreted as expressing the sense making of self and everyday activity in the interaction. The shifting response of the familiar self and the unfamiliar self suggest the bi-directional quality of the interaction. The responses of the familiar self and the unfamiliar self are the categories that describe how the PLWD and their spouse express attention to each other and their sense making process in the interaction.

In the first section, the findings illustrate the shifting responses of PLWD. The responses of the familiar self of the PLWD illustrate the sense making and the agency of the Tom, Sam, Paul and Evelyn when they refer to their past roles and accomplishments. Past roles are significant aspects of how they identified themselves now suggesting their continuity of self. Current responses of the unfamiliar self express that PLWD are unresolved. By describing this unresolved self they are trying to resolve who they are now and how to understand who they are in relationship. Responses convey how PLWD are receiving information on self and how this relates to who they are in relationship. Who they are in relationship are expressed as their continuity of self in past roles, in their relationship with their spouse or in immediacy of the interaction.

Shifting responses of PLWD express their sense making in the interaction. Compared to Tom, Sam, Paul and Evelyn, Harold's sense making is not related to his past roles but more explicitly related to the relationship with his wife. Harold's responses indicated that his sense making was connected to reinforcing what he has in common with his wife. Peter and Emmanuel are further along the dementia journey. Their sense making of self and of everyday activity occur within the immediacy of the interaction. Expression of their sense of continuity of self is evident in interactions in which their spouses are present and engaging in well established routine activities. In the first section responses convey how PLWD are receiving information on

self and how this relates to who they are in relationship. Who they are in relationship are expressed as their continuity of self in past roles, in their relationship with their spouse or in immediacy of the interaction.

In the second section, shifting responses of the intimate couple occur as they discuss everyday stories and relational stories. This shifting in responses is related to the spouses sorting out or making sense of their current context of dementia. Spouses tell stories about changes in their everyday activity and attend to each other while they tell these stories. In attending to each other the couples' response had distinct responses to their context of dementia. Karen engages her husband in the conversation and suggests how homecare services allowed them to be together in some way. Emmanuel responds to his wife with an utterance in which he recognizes she is talking to him. Mary looks to the everyday activities to monitor for symptoms of dementia. Tom responds by either concurring with Mary or by adding very little to her description. Alice suggests the increasing difficulty she is having in managing the everyday tasks as well as finding anything to share with her husband. Harold tries to bring a shared understanding to the interaction. In contrast to the other spouses, John's responses described how going to church had changed for the couple. In describing these changes his story includes the difficulties and contradictions he finds in trying to get Evelyn to go to church. Evelyn's response indicates her attention to the implications of these changes on her. She exerts her agency, her interest in being understood in the context of dementia. The responses suggest the agency of PLWD and how both spouses contributed to the creation of their new mutuality.

Attention to the shifting responses of the unfamiliar and the familiar self brings attention to how the context of dementia for the PLWD and their spouse involves PLWD re-interpreting self and the couples' reinterpretation of how to achieve everyday activities. Achieving everyday

activities as suggested in the excerpts occurs within a context of the intimate couples continuing interest in being in their relationship.

Chapter 5 describes how responses of PLWD and their spouse shape the mutuality being expressed in the interaction. In the first section, the intimate couples convey different styles of mutuality suggesting their process for making efforts toward mutuality and accomplishing their life together. In the second section the analytical framework is applied to different interactions of different couples. Applying the analytical framework for different interactions involves recognizing the individual contexts of each couple. However, the application demonstrates how the analytical framework could be helpful in discerning the interplay between the context of dementia and the relationship of the intimate couple.

## **Chapter 5**

### **Findings: Answering Research Question 2**

This chapter answers research question 2: How do the responses of the intimate couple shape their mutuality as a couple within the context of dementia? Answering question 2 includes describing how patterns of responses reflect styles of interaction between the intimate couples. Second, answering research question 2 describes how the intimate couple shape their mutuality to accomplish life together. It is in the back and forth of interaction that a sense of knowing ‘who I am in relationship’ and ‘how I know who am in relationship’ is established. The responses convey that spouses come to a new mutuality in their different context of dementia as they interact, manage everyday activity, and tell stories.

Previously shared ways of living such as ways of dividing tasks, sharing everyday activities and sharing relational stories change and are recognized as changed in the interaction. As the intimate couple recognizes these changes, parallel processes occur in the interaction that represents the PLWD and their spouse’s efforts toward mutuality. These parallel processes are about sense making and how this relates to what the PLWD and the spouse are bringing to the interaction. These are efforts that the PLWD and their spouse make to continue in their relationship together. Field observations are bracketed and bolded in the excerpts.

#### **Mutuality in the Dynamics of Responses and the Styles of Interaction**

The patterns of responses reflect three styles of interaction between the intimate couple: disrupting interactions, maintaining interactions and enhancing interactions. Responses shape the style of the interaction.

#### **The Disrupting Interaction**

In this interaction, both the spouses have responses that are primarily the unfamiliar self. Both are having difficulty understanding the self, other, relationship, activity or event in this

current context and both spouses express a lack of shared understanding about the meaning of self, other, relationship, activity or event.

In disrupting interactions, the PLWD and their spouse express difficulty in resolving an inconsistency between the current context of dementia and the past. They are having difficulty knowing who they are in relationship and how they know themselves in relationship. The shared understanding that the couple had previous to living with dementia is disrupted. Disrupting interactions identify unresolved sense of self and continuity of self. Things are not as they were before dementia (unrecognizable). Five excerpts from five couples illustrate difficulty in reconciliation related to the context of dementia.

### **Peter and Ruth**

Peter and Ruth rarely express disruption in their interaction however at times Ruth suggests that Peter's dependency on her and her increasing responsibility were making life stressful for her. In this excerpt, Ruth describes what Peter did for a living. Ruth's final response indicates a distancing as she indicates to Peter that he is no longer handy (disrupting):

**Ruth:** *He put up automatic fire sprinklers.*  
**Researcher:** *Okay.*  
**Ruth:** *And then he was an inspector.*  
**Researcher:** *Okay.*  
**Ruth:** *And if he built something it was built so it wasn't going to fall down (chuckle).*  
**Researcher:** *Oh wow. You were a handy person.*  
**Peter:** *Well at one time I guess I was.*  
**Researcher:** *Yeah. You're still handy in some ways?*  
**Peter:** *I don't know, am I still handy?*  
**Ruth:** *No.*

Peter himself appears not to remember what he used to do for a living. Peter's handiness is in the past, it was an aspect of Ruth and Peter's shared life together. This interaction identifies how Peter's handiness is no longer a recognizable aspect of their shared life (e.g., role specialization in the relationship). Ruth's articulation identifies Peter's current deficiencies.

Simply put, changes in Peter mean that everyday life and everyday activity has to be reconfigured. Everyday activity is no longer accomplished in the same manner.

### **Martin (PLWD) and Josephine (Spouse)**

Martin and Josephine had been married for 41 years. This is Josephine's second marriage. Josephine had four children from her first marriage and one child with Martin. They have two children who live in Winnipeg and who are available to help. Martin was 91 years old and Josephine was 76 years old. Josephine did not know what kind of dementia Martin had but said he had a number of 'small strokes.' The word dementia or even short term memory was avoided in joint interviews because Martin would become upset. Josephine had a history of lung problems and other circulatory issues but did not describe discomfort or difficulty during the interview. They were both independently mobile although Josephine did have a walker she used when she went outside. Martin had been living in supportive housing for 6 months prior to my first interview with them. Josephine and Martin continued to spend a lot of time at their home together. Two interviews were conducted in the residents' home and one in the supportive housing unit where Martin currently resided. The interviews at the home were in their kitchen. The one in the supportive housing was in Martin's room where we could speak privately.

In this excerpt, Josephine is responding to questions about changes in her and her husband's shared activities. The extent of Josephine's loss when she talks about Martin no longer wanting to watch their commonly enjoyed TV show together is evident. The disrupting interaction includes talking about how watching a TV program together has changed. In the exchange, both spouses contribute to a sense of moving apart from the other:

**Researcher:** *Do you, do you ever watch TV together?*

**Josephine:** *No.*

**Martin:** *No, very little.*

**Researcher:** *Did you used to watch TV together more, say, a couple of years ago?*



**Josephine:** *Oh yeah, yeah. We used to, that was sort of our, you know in the last five years for example it was Lawrence Welk and so we would have a happy hour and watch Lawrence Welk and then we would have dinner and then watch Lawrence Welk. And, and that was sort of our weekend entertainment right. (noted distinct sense of loss from*

**Josephine)**

**Martin:** *Yes, um-hmm.*

**Josephine:** *And we did that a lot. And then the other day...*

**Martin:** *More so than sports events.*

**Josephine:** *Right honey. Yeah. And then the other day I said, he was here and I said, will I put on Lawrence Welk and he said, who's he, he didn't want to watch it, so that's it, changes, things change.*

**Martin:** *Um-hmm.*

Josephine discusses the change in the shared activity of watching Lawrence Welk.

Martin follows the topic of the conversation (when he says “more so than sports”) but does not actively validate the underlying message transmitted by Josephine (i.e., the loss that she is experiencing now that they no longer watch this program). Both the change in a previously shared activity and his difficulty in recognizing the implications of these changes diminish Josephine’s experience of connectedness with her husband.

This next excerpt exemplifies how interaction in the context of dementia interrupts the shared activity of describing a common story.

### **Emmanuel and Karen**

In this excerpt, Emmanuel and Karen have a disrupting interaction because Emmanuel cannot participate with Karen in the telling of a relational story. This is the third interview with the couple. Karen does try to engage Emmanuel in the recollection of the event however, his difficulty following the topic of conversation leads to her trying to tell the story:

**Karen:** *Can you tell Barb what we do when we're there at his house, do you remember what his house near Seattle looks like and what we do (looking at her husband).*

**Emmanuel:** *Um-hmm.*

**Karen:** *One thing they like to do is play games right, play games. But sometimes we do something altogether. Do you remember what we do altogether there? (Looks towards Emmanuel.) We go on that special trail, right, for a long walk.*

**Emmanuel:** *Um-hmm.*

**Karen:** *But we have gone, we've gotten in the car and driven a long way and we've been able to go Sammamish Falls, so that's quite a strong river, kind of a mini Niagara Falls right (looking at her husband)?*

**Emmanuel:** *Yes dear.*

**Researcher:** *(Chuckle) Go along with her hey, that's the best idea (chuckle).*

**(Researcher is sitting beside Emmanuel on large couch – Emmanuel appears not be listening but rather responding to his wife's nonverbal cueing in the conversation)**

**Emmanuel:** *(Chuckle)*

**Researcher:** **(I point to a picture close to a window that hangs on the wall).** *So, this a picture of all your family?*

**Emmanuel:** *Yes. And then we go (chuckle) and then we go to this, there it is a black bird.*

**Researcher:** *Black bird?*

**Emmanuel:** *Yeah*

**Researcher:** *You're seeing a black bird.*

**Emmanuel:** *Yeah, he just took off*

**Researcher:** *Oh yes, I see yes.*

**Emmanuel:** *You see yes.*

**Researcher:** *I see, I see that it took off,*

**Emmanuel:** *(Chuckle) thinking about the bird and saying why don't they just come and fly some of them.*

**Researcher:** *They do.*

**Emmanuel:** *Some of them do, but there are several of them that don't.*

**Karen:** *Were, were you telling Barb what Eric, you and Eric did when he was here.*

**Emmanuel:** *Well I just happened to look up and there it was a black bird that went and just stopped on one of those...*

**Researcher:** *Trees.*

**Emmanuel:** *...very lovely trees.*

**Karen:** *Um-hmm.*

**Emmanuel:** *Yeah. And said thank you very much, however we have to go and get the right kind of bird and yeah and we have been trying to keep them.*

This excerpt reflects difficulty in Emmanuel and Karen's shared understanding because by the end of the interaction they are talking about different topics. Karen may also be concerned with maintaining shared understanding within the immediacy of interaction with Emmanuel. Her response may be an attempt of sense making within the interaction to resolve the inconsistencies in her understanding of who she is in her relationship with her husband.

Karen's responses are unusual in this interaction. Her most common style of interacting with her husband has been to follow his lead and as much as possible engage him in the conversation. In the first part of the interaction, Karen tries to engage her husband in the topic of family walks. He is unable to follow, and his verbal responses indicate that he is distracted. Karen does not follow his topic change when he begins referring to birds. Her attention to describing her family visits and walks, and not changing topic suggests disconnection in the immediacy of the interaction. Telling her story seemed to become more important than being positively engaged with her husband. This took away from her interaction with her husband. I respond by engaging with Emmanuel to see if she would re-engage with him.

Karen's story may reflect her making sense of self. She is describing herself as she knows herself to be in relationship with her family and her husband. Perhaps it is important to reflect on how she used to have mutuality with her husband in order to make sense of how to have mutuality with her husband in her current circumstances.

Emmanuel is unable to recall and engage in Karen's story telling; he remains engaged in so far as he makes comments in turn and when he is directly spoken to. Emmanuel may be showing agency in switching to a topic that he can relate to in the present moment.

### **Paul and Elizabeth**

In the following excerpt Elizabeth and Paul are having a disrupting interaction because Elizabeth has changed the way she interacts with Paul. Everyday activities have changed and Paul does not remember what day it is. Elizabeth's response to his not remembering is, at the recommendation of their family doctor, to tell him that he needs to look at the calendar. In this excerpt Paul expresses his response:

***Paul:** Yeah. And it's not getting better, it's getting worse, I, I feel that you know it's, she's playing a game with me.*

**Elizabeth:** *And he, he, I know it's because he needs that information or he needs that done and it doesn't always happen as fast or the way he would like.*

**Paul:** *No, a simple thing like for example "Elizabeth" what, what day is it today.*

**Researcher:** *Um-hmm.*

**Paul:** *Why don't you look on the calendar? (Paul is mimicking Elizabeth)*

**Paul:** *I didn't, that's why I didn't ask you that, I asked you what day it is.*

**Paul:** *'Cause you know what day it is and I feel now she's playing a game with me you know*

The context of dementia is impinging on the interaction between Paul and Elizabeth. Paul is perceiving that Elizabeth is responding to him differently than she used to respond to him. Elizabeth is expressing the increased demands because Paul is asking more questions than he did before dementia. Paul and Elizabeth are not sharing an understanding about how they should interact. In fact, they are not speaking to each other, but about each other (third person referencing). They appear to be speaking to the researcher.

In this expression of their differences, of stating how things are not the same to each other, both may be attempting to accommodate to the best of their abilities to their context of dementia. Paul interprets Elizabeth's redirection to the calendar when he asks her a question as hurtful. Paul describes his current self as unresolved from his past understanding of self. He is not who he knows himself to be in relationship. Elizabeth's description suggests that she is unsure of how to deal with his demands. In this interaction, the context of dementia is a threat shared understanding.

### **Harold and Alice**

In the next excerpt, Alice and Harold are having a disrupting interaction because of the broader social implications of dementia. Harold has been listening to the arguments in the recent media about the "right to die" legislation. Harold recognizes the strain his dependency has on Alice. He recognizes that as his dementia progresses, this dependency will increase. In

consideration of this he brings up in the interaction this legislation and suggests that he would like the right to die. This excerpt is a portion of this discussion:

- Alice:** *So let's, let's make the most of what we've got while we've got it.*
- Harold:** *But it's hard for me to balance that out with what it takes out of your life to have to be dealing with my head all the time.*
- Alice:** *Okay, but I'm going to worry about that, I'm going to look after that part okay.*
- Harold:** *Well I don't think, I can't see the, the...*
- Alice:** *Okay reverse it. If I needed you to look after me...*
- Harold:** *Um-hmm.*
- Alice:** *What would be the difference in how you would, would you want me to take the needle and leave you?*
- Alice:** *Well I need to know, because that's what you're telling me.*
- Harold:** *Yeah but what I'm doing by doing that is giving you part of your life back.*
- Alice:** *Well that's, that's a noble thing, but maybe, you know, if I'm saying I don't need you to do that, I need you instead. I mean would you not want me to be around for you if, if it was reversed.*

Though Harold identifies Alice's difficulties, he refuses to capitulate to her greater concern that suggests his value in spite of his dependence. She reaffirms her connection to him ("I need you instead. I mean would you not want me to be around"). Alice's responses do not redirect Harold's concerns suggesting that he regards himself as less of a person because of his dependency. It could be that societal values of independence are an aspect of his response and make it difficult for him to have a shared understanding with his wife.

Harold's responses need to be understood in the context of his current and anticipated increasing dependency; he is keenly aware of the increasing demands on his wife and anticipates a decline in his connectedness with his wife in the context of dementia. Harold's expressed dependency towards his dementia is an aspect of much of the interaction between him and Alice.

### **Summary of the Disrupting Interaction**

Each of the excerpts above highlights aspects of the context of dementia that disrupt shared understanding or mutuality in the intimate couple. The context of dementia unfolds for each couple as they interact, and the disrupting interaction could suggest an impasse on how to manage dementia. The context of dementia illustrated in these interactions is: roles changes; changes in shared activities including the ability to share previous relational stories; change associated with how everyday interactions; and unresolved fear and discomfort associated with the increased dependency of dementia.

### **The Maintaining Interaction**

In the maintaining interaction one of the spouses have responses of the familiar self and the unfamiliar self, or one spouse changes from a response of the unfamiliar self to a familiar self. In maintaining interactions, one spouse communicates difficulty with shared understanding, while the other is engaged or interested in shared understanding or one spouse changes from expressing difficulty in shared understanding to an interest in shared understanding. Two processes were identified as connected to this style: preserving and mending.

#### **Preserving**

Preserving involves one of the spouses invoking a past understanding about self, other, relationship or activity that connects the couple, thereby reinforcing that past shared understanding in interaction with their spouse. This orientation to the past conveys an implicit expectation that their past shared understanding should be reflected in or continuous with their current understanding.

#### **Mending**

Mending involves one spouse's responses in the interaction suggesting a process of re-framing the meaning of what it is to be in relationship involving their accommodating or adjustment or accepting of the changed circumstances of the everyday activity of the spouses.

Examples of both processes are illustrated in six different excerpts below and connected by an exploration of efforts toward mutuality in the context of dementia.

### **Martin and Josephine**

Martin demonstrates preserving when he expresses his understanding of who his wife is in their relationship and attempts to use his understanding of her from past interactions to frame a current shared understanding. I asked Josephine how things have changed for her in the last five years:

**Josephine:** *Well, I've had serious illnesses a year ago and that seems to have slowed me down. I have COPD which also slows me down, you know like today I had difficult time breathing for a little while.*

**Martin:** *Is that right?* (Is concerned and is unaware of his wife's illness)

**Josephine:** *But it seems to have passed, yeah.* (**Minimizes her situation so as not to upset him**)

**Martin:** *Well you didn't tell me that.* (**Upset he wasn't informed; not recognizing or wanting to admit his memory is such that he cannot keep track of these events**)

**Josephine:** *Well I used my puffer when I went to pick you up. But that was okay, like that happens and it passes. And mostly I, I'm thankful that I can do what I can do because I've had this for a long time and the doctor, the respirologist said you know usually and it isn't always the case, but the average lifespan is about ten years and this was 12 years ago.*

**Researcher:** *And you are OK?*

**Josephine:** *And, and with five years you know on oxygen and I'm not on oxygen and so I'm just...*

**Martin:** *She's a people person.*

**Researcher:** *Yes, that's for sure.*

**Martin:** *(Chuckle)*

Josephine's description of her chronic condition signifies her difficulties in her current situation. Martin's initial response ("you didn't tell me") indicates he is listening and may be concerned. Josephine's difficulties were unrecognizable to Martin. His response later ("she is a

people person”) is not “in sync” with what his wife is talking about and redirects attention to an aspect of their relationship that is familiar. He preserves his understanding of his wife and emphasizes continuity, while at the same time preserving his sense of self despite being unable to acknowledge his wife’s current difficulties.

### **Tom and Mary**

Preserving is exemplified in an excerpt in which Mary and Tom, tell a story about a hobby they shared when they lived in Germany. In this story telling, Tom focuses on their shared activity, but Mary does not recognize this in the interaction. Her focus on correcting Tom diminishes his attempt to construct a shared understanding through mutual telling. The background to this story is that they belonged to a hunting club when they lived together in Germany:

*Tom: We would go to the pub after shooting. Mary could outshoot anyone. They had a protocol there that if any of the hunters were a little dangerous the way they handled their guns or did something that was not part of the guidelines and regulations, at the end there they’d have a court, a hunting court and they’d generally have it in a pub and the hats would be turned upside down to go on the heads and there was a judge there and there was a prosecutor, the other one.*

*Mary: Defense.*

*Tom: And it was lots of fun.*

*Mary: Defense.*

*Tom: Yeah.*

*Mary: Prosecutor and defense for...*

*Tom: Yeah and it was a lot of fun, but the message got across without being harsh about it you know.*

*Mary: And depending on the infraction...*

*Tom: Yeah*

*Mary: ...do you remember what the penalty might be.*

*Tom: Oh yeah.*

*Mary: Do you remember?*

*Tom: Yes...*

*Mary: No what would the first one, for a simple infraction what would it be, do you remember?*

*Tom: Oh two litres.*

*Mary: A jager litre of wine.*



**Tom:** *A jager litre of wine.*

**Mary:** *Which is two litres of wine.*

Tom's responses are focused on a past shared activity between him and Mary (i.e., preserving their story). He compliments Mary's ability to shoot and appears to be attending to the part of Mary's story that is connected to their shared story. In the story that Tom tells he is preserving his understanding of their shared life together (Mary's response interrupts this).

Tom's preserving expresses the value he has in sharing activity and a past with Mary.

Some of the stories that other couples recount pinnacle events that identify or denote their changing circumstances— rather than preserving, these stories represent interactions that were disrupting. Pinnacle relational stories provide a backdrop to review current circumstances and identify how these past stories become integrated into newer emerging meanings of everyday circumstances. In these next excerpts, the telling of the story reflects a mending process in which one or both spouses attempts to reconcile or reframe the situation and its meaning for their relationship.

### **Sam and Roberta**

In this excerpt, Roberta relays a pinnacle moment that inspired new meaning for her life with her husband with dementia, and may signify mending. Sam's interjections, however, suggest attempts at preserving.

**Sam:** *And so I wanted to see the rest of the wall of China. And of course I was stupid, I mean I, I knew if I said to Roberta I wanted to do this, she'd say "Sam" there won't be time, come on, and I just made a very selfish decision and not to say anything to her to do this, but I had no idea of the scale of what I was dealing with.*

**Roberta:** *But, but the main problem was he didn't recognize where the van was, he didn't recognize where to stop.*

**Sam:** *Well I didn't, well I didn't realize I'd gone down on another level of, of wall either.*

**Roberta:** *Yeah.*

**Sam:** *I mean I was, yeah.*

**Roberta:** *He, he was disoriented.*

- Sam:** *Yeah.*
- Researcher:** *Did you, do you remember feeling that way, disoriented or?*
- Sam:** *You know I just, no I thought, I thought I was on the same level somehow, I thought, I didn't know that I'd gotten down to a lower level and the one they would be on. I didn't, I can't recall seeing a, you know, separation of the two. And maybe when I got to the separation I just assumed you know 'cause I hadn't really registered that there was another union here as I'm going by.*
- Researcher:** *'Cause was this was a totally different thing that he had done, he'd never done anything like...*
- Roberta:** *No, no. And because you know his behaviour influenced other people I was feeling.*
- Researcher:** *Felt embarrassed (chuckle).*
- Roberta:** *It was embarrassing.*
- Sam:** *Yeah.*
- Roberta:** *And sort of you know...*
- Sam:** *Well they were worried about me too.*
- Roberta:** *Yeah, yeah, initially worried and then...*
- Sam:** *Frustrated.*
- Roberta:** *...well initially frustrated and then worried and then well where can he be sort of thing.*
- Sam:** *Yeah.*
- Roberta:** *And so yeah it was, it was a deal that he just, he just...*
- Sam:** *I didn't stray after that.*
- Roberta:** *No.*
- Sam:** *No, no they were, they were really, really good. I mean I could see what I had done to them you know and that wasn't...*
- Roberta:** *He had just been diagnosed with dementia. So they did know. Up to that point he was functioning*
- Researcher:** *You hadn't had any extraordinary like this happen...*
- Roberta:** *No, no.*
- Sam:** *No, 'cause I'm still reasonably good at orientation, like I could walk almost anywhere in this area.*

The story of their experience at the Great Wall of China represents mending for Roberta - a process of accommodating and adjusting to what it means to be in relationship with a person with dementia. In the story telling there is initially a sense of diminished shared understanding between her and Sam. Roberta's statement "but the main problem was he didn't recognize where the van was, he didn't recognize where to stop" conveys the problem she is now encountering (his memory loss, its unpredictability, and her ongoing concern about his safety).

Her comment describes the emotions she experienced then and perhaps what she experiences now: sense of being frustrated with him, to being worried about what could happen, to a feeling of just wanting him back.

Sam's responses reflect preserving - he acknowledges his errors and the stress he caused his wife and others. Sam's comment that he has not strayed since may represent an attempt to maintain continuity of valued self-identity. It also acknowledges Roberta's concerns as he reinforces his ability to remain oriented in his own neighborhood.

### **Harold and Alice**

As in the story told by Roberta, it is suggested that Alice initiates a story about the decision not to travel by pulling a trailer in part to resolve aspects of their current context of dementia. Unlike Sam, however, Harold does not suggest he understands her distress. In the story telling, Alice seems to come to recognize the significance of having this good memory of her and her husband together. Their story is about an event that occurred in 2002 and was referred to twice in the joint interview conducted with Harold and Alice. Around this time Harold was having increasing difficulty with activities of daily living and Alice had to take an increasing role. He was diagnosed with a vascular dementia around this time. Alice had described contending with re-organizing their everyday activities related to his physical and mental changes since 2002. She describes a pinnacle time in their lives:

**Alice:** *Well one of the things that goes back even before '02 is this 5th wheel, there were two or three times he scared me to death in trying to do the steps that it takes to get that properly and safely hooked up and unhooked and whatever. And we had some real upsets over that and he was very resistant to me suggesting he didn't always do what he was supposed to do.*

**Researcher:** *Um-hmm. So it was a safety issue.*

**Alice:** *For me it was and he was very angry with me because I forced the sale of this and I really took over and forced it and that really made him bitter for a long time about this. But he could not see what I could see.*

- Harold:** *She was very upset. We were coming back home from the south in the early spring and we went into a place off of I-29 south of in South Dakota. And I'm turning (inaudible) I didn't realize it but the (chuckle) the trailer was about at that kind of an angle because I had pulled it around too sharp.*
- Alice:** *That was just one of the many things you know.*
- Researcher:** *So, so when you look back on it right now do you see that Alice was right.*
- Harold:** *Oh yeah (chuckle).*
- Researcher:** *And you have a sense of humour about it. But at the time it was, do you remember how angry you were (I am talking to Harold but Alice responds)*
- Alice:** *No, I was angry, he, he told me I was crazy you know, there's nothing wrong.*
- Harold:** *You see she couldn't explain to me what she was talking about.*
- Alice:** *Yeah, that's another thing trying to explain things to him, it was very difficult because he just could not either hear what I was saying or didn't get the gist of what the concern was.*
- Harold:** *Now we're getting down to the good stuff you see (chuckle).*
- Alice:** *No, I mean this is...It's, it's only recently that he hasn't been really furious with me about it though. Very blaming.*
- Harold:** *If I could get somebody to drive it, I would like to go and buy another one. You can really enjoy yourself. That was about the best travel stuff...*
- Alice:** *That's right (chuckle). Yeah, it was wonderful.....While it lasted*

As Harold and Alice tell their story about the 5<sup>th</sup> wheel Harold is preserving the fond memory of a mutually enjoyable past shared travelling experience (e.g., “that was the best travel stuff”). Alice conveys events that led to discontinuing travel and to her decision to sell the trailer. The telling of the story involves a description of strong emotions and conflict that continue to be a current aspect of their everyday life together. Harold's preserving of the good things about driving the trailer seems important. He perhaps derives some sense of control in a situation in which he experiences little control by his almost surprising suggestion that they purchase another trailer (albeit “if I could get someone to drive it”). Alice's descriptions represents a mending process – in that she does not argue his need to preserve his memory by imagining they could travel like this again but rather reinforces that it was an aspect of a shared life together in which there was a positive mutuality ( “Yeah, it was wonderful while it lasted”).

## Evelyn and John

In his interviews, John characterizes him and Evelyn in the past as a ‘team’ (e.g., they both stood up for social justice and community and he spoke about how they supported one another during tough times). He describes Evelyn in the past as sharing the same values as he (e.g., “So it was that kind of a thing that she stood up for”). Recently, however, Evelyn has expressed criticism of John’s past behaviours, challenging his perception of them as a ‘team.’

In the following excerpt, John does not relay a specific story, but rather describes interactions with Evelyn that represented this shift in their shared understanding. John mends his understanding of Evelyn’s responses in the current context.

**John:** *So, we’ve been a team. And one of the key things is where we worked as a team before, all of a sudden this was a, kind of a burden and where she was seeing that I had lost my jobs because I couldn’t handle the jobs instead of seeing the reason for it. For example, when the, my inspector or supervisor transferred me from Leaf Rapids to Granville they had a petition wanting me to stay. (John speaks rapidly and it is hard to follow what he is saying at times).*

**John:** *And what’s happening now is that I think that there’s more teamwork, we’re working, we’re together again and trying to cope with a difficult situation.*

**Researcher:** *When you reflect back on the difficulties you have had recently, you feel this recent diagnosis the difficulty, it helps your understanding of the change better.*

**John:** *Yeah.*

**Researcher:** *And did that help you understand a little bit (looking at Evelyn), did that help understand that.*

**Evelyn:** *John wasn’t always the easiest person to get along with, let’s face it (chuckle) he had his problems (chuckle).*

**Researcher:** *(Chuckle).*

**Evelyn:** *(Chuckle) It’s not a one-sided thing.*

**John:** *No, I hope I’m not giving that impression (chuckle). It was just that she and I were both alike. She stood up for things just like I did.*

John perceived his past difficulties as related to social injustices and understood that Evelyn supported his decisions and actions based on their common shared understanding of social justice. In this excerpt, he expresses his desire to preserve this aspect of who he is and how he understands their relationship. In contrast, Evelyn’s current responses dismiss this idea

of a past shared understanding or a sense of mutuality between them. She is critical and speaks of John in the third person. She may be responding to the implication that her dementia has disrupted her reasoning. Although Evelyn's response (to voice her discomfort) may preserve a sense of self-continuity, she remains engaged in the topic in a light-hearted manner. John also describes his discomfort that Evelyn's evaluation of his past behaviour suggests that they were not the team he had thought they were. Yet, within the immediacy of this interaction, the couple come to arrive at some shared understanding when John agrees that he was not the easiest person to live with.

This type of interaction shows John's efforts to mend his previous understanding of their shared value. John conveys to Evelyn the significance of being on a team. To John, 'being a team' connects his current self to a sense of a consistently defined relationship with Evelyn. While John mends his understanding of who they are in relationship, Evelyn's responses suggest she is preserving who she knows she is in relationship as a distinct human. Evelyn's apparent rejection of John may establish her distinctness from him and offer her a way of understanding her circumstances beyond the purview of dementia. Her previous connection to her husband may have hinged on her own independence and ability to make her own decisions separate from him. John is mending this rift between them by understanding her need to express herself and her differences. John states that they are working as a team in a difficult situation which I interpret to mean his reframing of mutuality with his wife in their current circumstances.

The context of dementia includes Evelyn's memory loss about recent events and decreased motivation. John's communication style<sup>1</sup> may exaggerate Evelyn's difficulty in interaction with him. She may find it difficult to interpret his meaning. In part, this may also

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<sup>1</sup> It should be noted that John talks in a way that is difficult to follow (he assumes a lot of co-existing understanding and often intermixes several ideas within one statement.)

explain why she distances herself from his interpretation (e.g., that the dementia has made her less inclined to reassure John about his life choices).

John's understanding of what it is to be in relationship with Evelyn is shifting under the circumstances of dementia. This type of maintaining (mending) interaction entails sewing a new understanding into the fabric of the couple's relationship. In the mending, Evelyn's distinct self is preserved.

### **Peter and Ruth**

In the next excerpt, mending occurs when Ruth shifts her response in interaction by recognizing her husband's efforts for shared understanding. Ruth adjusts the way she is talking to be more inclusive of her husband because he asks for clarification:

**Ruth:** *He used to barbeque and he used to like to do some things, like he, the, the bread maker and that, he used to play with that but he doesn't do that anymore and he doesn't barbeque anymore. The last time he barbequed I had to run in and out and keep checking 'cause he couldn't even keep track of the time so (chuckle).*

**Peter:** *How come we are not barbequing...*

**Ruth:** *I don't know why, why were you were in such a mess that day, but, so we'll have to start barbequing again, get you out there again.*

Ruth described Peter's barbecuing difficulty which had changed the dynamics of their life together. She responded to Peter's request for clarification about why they were no longer barbecuing. Ruth was mending her own understanding of what it is to be in a shared life with her husband.

### **Summary of the Maintaining Interaction**

The responses of the familiar and unfamiliar self of the PLWD and the spouse reveal how each spouse pays attention to the other in the interaction. The analysis of maintaining illustrates how a spouse's responses preserve who they knew they were, or they mend or reinterpret their understanding of the changes. For instance, acts of recalling and articulating past selves, others

or activities helped PWLDs maintain mutuality with their spouse. In the maintaining style and mending interaction, spouses foster the abilities of the PLWD or they reflect on their own interpretation of events and reframe the meaning of the interaction. These responses shape the couple's sense of mutuality (or shared understanding).

### **The Enhancing Interaction**

Interactions are enhancing when each spouse positively engaged the other in their shared understanding of self, their relationship, event or activity. Positive engagement includes bringing a sense of continuity of self and everyday activities. These interactions highlight how the intimate couple's efforts toward mutuality involve bringing their past selves and past activities into their current situation. It shows how their responses are shaping their mutuality in their current context of dementia.

The activity that the couple discuss in the interaction fosters positive shared understanding or mutuality in its past recollection and remains in its current telling. The spouse responds to the ability of the PLWD in the interaction and maximizes the PLWD agency to contribute in the interaction. These enhancing interactions highlight how the PLWD is more than a person with dementia to their spouse. It is suggested that the enhancing style of interaction is or can be part of a process in which the couple expresses a new type of shared understanding in their context of dementia. The enhancing style of interaction exemplifies the couple's interdependence to create a new shared understanding or mutuality in their continued life together. Examples of enhancing style of interactions from six couples are provided.



### Martin and Josephine

In this excerpt the couple discusses a past shared activity of dancing together. These past recollections promote or reflect enhancing. The interaction begins in response to the question I pose as the researcher:

**Researcher:** *Is there anything that you remember that you have done together, all the time when you first got married or first started seeing each other?*

**Josephine:** *Dancing. We did a lot of dancing.*

**Martin:** *Yes, we went to a lot of dances I think yeah. (Engaging in the conversation)*

**Researcher:** *Very good. That's less common now you know.*

**Josephine:** *It really is, I mean we, we danced at our daughter's wedding I think was the last time I think that we danced and that would be ten years ago. And people said, different ones, mostly from the other side of the family like from our daughters in-laws, said, did you two take dancing together and we never had, but we just always danced together like for 40 years you dance together, you're going to get so you know where the other one's going to step, you know you're not going to walk on each other's toes.*

**Researcher:** *That's so interesting, yeah that's very interesting.*

**Martin:** *Yeah. Waltzes and polkas.*

**Josephine:** *and Foxtrots.*

**Martin:** *Foxtrots.*

**Josephine:** *Years ago we used to do square dances and stuff but they don't do any of that, haven't done that for years, but when we were first, first dating we used to do those once in a while.*

**Martin:** *Once in a while yes.*

In this excerpt, the intimate couple recognizes the common activity in which they both engaged, and their interactional responses reflect mutual acknowledgment. Both spouses are engaged in a broader process of shared understanding.

In this excerpt, Martin's continuity of self in the relationship is evident in his engagement through novel and appropriate responses to the discussion of dancing. Josephine's recollection of their past pleasurable activity in which they both engaged reinforces continuity of who she was as a distinct person, and who she is in relationship with her husband.

In this interaction, Josephine initiates the story about dancing together, providing enough information so that Martin can recall their dance moves. How well he remembers this activity is unclear, although he does remember the name of certain dances and contributes to the content of the conversation (adding novel and appropriate comments). However, he is limited in his ability to initiate recollections of shared activity and for the most part relies on Josephine to do this within the interaction. Josephine does not press Martin to remember specific dancing occasions. Notably, Martin does not join Josephine in recollecting their daughter's wedding. The process undertaken by the intimate couple in this enhancing interaction suggests their interdependence as their responses to each other foster their mutuality.

### **Paul and Elizabeth**

Like Martin and Josephine, Paul and Elizabeth discuss past activities; exemplifying who they know themselves in relationship and how they know themselves in relationship with their spouse. The following excerpt is an example of how both Paul and Elizabeth see themselves as being on a team and helping each other to accomplish goals. Paul is describing how Elizabeth helped him with completing assignments:

**Paul:** *Any time I needed help I knew where I could go.*

**Researcher:** *Like she did part of it for you.*

**Elizabeth:** *(Chuckle)*

**Paul:** *Well no, we did it together you know.*

**Elizabeth:** *Yeah it was a good; well we've had a good team approach to life.*

**Paul:** *Yeah, yeah.*

**Elizabeth:** *And that's worked for us.*

Paul and Elizabeth share this understanding of their relationship (that in the past they had been a team). Elizabeth's comment that teamwork "worked for us" highlights their sense of distinctiveness as a couple. Paul has continued ability to engage in verbal interaction and to reflect on the meaning of past activity. Elizabeth's interest in recognizing and reaffirming past

common events reinforces who they were and are as a couple. The discussion of these former activities in the present reinforces the couple's sense of commitment within the difficult context of dementia. The enhancing style of interaction conveys the couple's strength in their connection. Paul and Elizabeth's enhancing style of interaction reflects strategies to strengthen this connection by recollecting and emphasizing their past shared accomplishments. In the next interactions between Evelyn and John, strategies to strengthen connection are also illustrated in common shared positive memories.

### **Evelyn and John**

Evelyn's dementia has not impeded her capabilities to contribute to a shared activity of storytelling in this next excerpt. Similar to Elizabeth in the last excerpt, John reinforces Evelyn's accomplishments. The couple describes their first fall harvest after being married, which John raises as an example of Evelyn's strong relationships with both of their sets of families:

- Evelyn:** *Yeah. We didn't get together as often with my family but...*
- John:** *Well we were further away, you had a good relationship when we lived with our family. An example for me is when we got married, the first fall I'd be going home to help with the harvest at home and we came down a Saturday and dad had land spread out on the reserve and another place and all the grain, he had old trucks and he needed a driver, and she drove down the river road (chuckle) with a big truck full of grain or empty.*
- Researcher:** *Evelyn you were never intimidated by doing anything, you just did it (Looking at Evelyn, trying to include her in conversation).*
- Evelyn:** *No, I told dad, I don't think I can drive it, and he says, yes you can, here's the key.*
- John:** *And each truck is different so that was another thing that she had to learn.*
- Evelyn:** *He had more confidence in me than I did myself probably.*
- John:** *There was a good relationship with both sides of the family. When her sister died she looked after her parents and I looked after her parents. So that was the relationship on the other side. So this is what I'm saying.*
- Researcher:** *A lot of, a lot of good connections.*
- Evelyn:** *Oh yeah.*

Each partner supports the others positive recollection of Evelyn's achievements during the harvest in this enhancing interaction. This excerpt exemplifies how both spouses are

bringing a sense of continuity of self and everyday activity to their interaction. Evelyn is able to recall these specific events which can remind her of her past abilities, and displays reflective capacity in her comment that “they had more confidence in me than I had in myself.” John is reinforcing a sense of continuity for Evelyn. By bringing up these positive attributes about Evelyn in the past he is reinforcing who she is in the present. She is more to him than a person with dementia.

### **Sam and Roberta**

In the following excerpt, Roberta describes how the couple organizes their evenings. Roberta’s responses in the interaction suggest a matter of fact manner in her tone. The way she talks and how she describes their relationship reinforces a sense of closeness while also identifying Sam’s increasing dependence on Roberta. This excerpt reflects an acceptance or comfort level with their current circumstances that may be a result of their continued ability to work together to ensure ongoing shared understanding:

**Roberta:** *So, so I guess the other thing is, I mean our life right now is, is fairly entwined so I was even thinking you know after dinner the routine is go down and watch the news and, and then pick some Netflix or whatever, so the evenings we’re usually together. For the entertainment business. And then you know on an afternoon if it’s quiet we’ll both sit and read together, so you know there’s, we’re always sort of within arms’ length it seems.*

**Sam:** *Shouting distance (chuckle) yeah.*

**Roberta:** *Yeah.*

**Sam:** *Yeah.*

Roberta describes their current relationship and life together as “entwined.” The humour in relation to this, and the mutual recognition that they are entwined (i.e., interdependent) highlights this as an enhancing interaction. Their recognition within the interaction of their interdependence fosters their mutuality. Both Roberta and Sam are connected through their continued ability to appreciate the activities that they can engage in together. Sam’s verbal abilities and accepting personality facilitates this enhancing interaction. Elsewhere in the

interview, Roberta and Sam comment that the context of dementia means that each partner is more aware of where the other is within their environment.

### **Emmanuel and Karen**

Sam, Paul and Evelyn all remain able to recall certain events and respond to some of the interactional dynamics; they share understandings with their spouses about past events, which facilitate enhancing interactions. This is not the case for Emmanuel and Karen, but nevertheless, enhancing interactions do occur. In this next excerpt, Emmanuel and Karen share an activity of photo-selection and photo-elicitation that does not engage a discussion of who they are as a couple or require recollection of past events; nevertheless, the interaction conveys *enhancing* and can promote and reflect a sense of mutuality. The couple is selecting the photographs that they like the best from the photographs I had taken of them the previous week:

- Karen:** *Well that's a nice picture.*
- Emmanuel:** *Um-hmm, um-hmm.*
- Karen:** *That one didn't turn out very well, so I guess that wouldn't work, hey **(looking at Emmanuel)** for her. She needs to be able to show this picture, nobody would understand that hey **(looking at Emmanuel)**, what do you think? Same with that. What about that one?*
- Emmanuel:** *What about this?*
- Karen:** *Wow, there's my European husband...*
- Researcher:** ***(Emmanuel is looking through pictures and stops at one)**. You stop at that one. You like that one, that's a picture of you and...*
- Karen:** *You and who, who's this.*
- Emmanuel:** *Yeah.*
- Karen:** *Who's that?*
- Emmanuel:** *That's my wife.*
- Researcher:** *That's a picture, that's one you like hey.*
- Emmanuel:** *Yeah.*
- Karen:** *Hey. Do you think that's a good one?*
- Emmanuel:** *Yeah.*

Karen remains engaged and on topic with Emmanuel during the interaction that engages them in shared activity and opens opportunities to reinforce shared understanding. Karen's attention to Emmanuel involves making adjustments in the interaction. By doing so Emmanuel

demonstrates the ability to engage with his wife and ability (albeit conditional) to attend to the situation. Karen provides verbal and nonverbal prompting, responding in ways that are easy for him to follow; she demonstrates ongoing interest in supporting her husband to optimize his abilities in interaction. Karen is instrumental in maximizing the enhancing interaction.

### **Harold and Alice**

In this next excerpt, Harold and Alice are looking at the photographs of themselves, deciding which the best one is, and describing it. In this *enhancing* interaction, reflecting a shared understanding, Harold is not as far along in the dementia process as Emmanuel; however, Alice also actively engages her husband in the activity of photo-selection and photo-elicitation.

- Alice:*            *What does this picture say to you?*  
*Harold:*           *He was having a chat.*  
*Alice:*            *Yeah.*  
*Harold:*           *Hmm?*  
*Alice:*            *Okay, you're waving your arm. Did you notice?*  
*Harold:*           *Which?*  
*Alice:*            *You're waving your arm.*  
*Harold:*           *Yeah, I guess it is moving isn't it; I'm emphasizing something I guess.*  
*Alice:*            *Yeah, emphasizing okay.*  
*Harold:*           *Yeah, smiling again, I got to watch that.*  
*(Laughter)*  
*Alice:*            *Well this part, this is one of my favorite pictures of you because you look happy.*  
*Harold:*            *Um-hmm.*  
*Alice:*            *And that's nice to see.*  
*Harold:*            *Yeah I'm as happy as I can be I guess. I like that one.*

Harold and Alice are both focused on describing what is happening in the photograph and deciding which of the photographs are the best. Though Harold's response includes his ambiguity, the couple demonstrates efforts toward mutuality by both agreeing that one of the photographs is nice because Harold looks happy. The activity facilitates relational connection and mutuality. Yet it is unclear whether Harold's initial response to the photograph (describing the person as "he") means he is not paying attention, or he does not immediately recognize

himself. He does follow the rest of the conversation and contributes novel comments. He makes a joke about himself in describing the difficulty he has in seeing himself as happy. Alice consciously engages with her husband, as did Karen in the previous excerpt. Both spouses appear to recognize and use opportunities for shared understanding within the interaction.

### **Summary of the Enhancing Interaction**

The above six excerpts illustrate interactions and responses with the potential to enhance mutuality within the context of dementia. For instance, these interactions engaged each couple's abilities to recollect past perceptions of self, other, activities or events, to validate each other's descriptions, and to express shared understanding in the back and forth conversing as both spouses recall past events or share an activity together. The enhancing interaction identifies how agency of the PLWD is maximized by their spouse to foster and support their mutuality as a couple. Enhancing may also be indicated through positive relational engagement in the immediacy of the interaction (e.g., currently having a mutually enjoyable experience) that involves the spouse recognizing and engaging with PLWD.

### **Summary in the Dynamics of Responses and Styles of Interaction**

The efforts toward mutuality of the intimate couples are illustrated in the styles of interaction. Recognizing the style leads to understanding that the context of dementia is embedded in how each spouse attends to the other. The style expressed by the couple could be responses to the changing symptoms of dementia, the perceptions of dementia including the broader social implications of dementia. Styles of interaction could be related to the PLWD response to changes in the interaction and it could be related to the changes in everyday activity. Styles of interaction as identified here could also be related to the expression of unmet needs. I have provided examples of excerpts which exemplify the different styles of interactions that were identified in the joint and individual interviews of the intimate couples. Disrupting,

maintaining and enhancing interactions occur for all of the couples. Couples exhibited differences in the amount of shared understanding in their interactions (disrupting, maintaining, enhancing) consistently throughout their interactions. These different styles are suggested to be an aspect of a process in which the couple is creating a new mutuality in their current context of dementia.

In disrupting interactions, dementia makes the current interaction unrecognizable to both spouses; it has disrupted their current ways of understanding. The responses in the disrupting interaction are primarily responses of their unfamiliar selves. In maintaining, the responses of one or both spouses serves to either preserve a current or past shared understanding of the intimate couple, or mend interactions through resolving the context of dementia into a new or reframed shared understanding. In the maintaining style of interactions responses are of the unfamiliar self of one of the spouses and responses of the familiar self of the other, or they are the changing responses of the unfamiliar self of one spouse to a response of the familiar self. Enhancing occurs when the intimate couple together recognizes the shared understanding within the context of the interaction. In this enhancing style of interaction, responses are primarily responses of the familiar self.

There is variation in how each couple makes efforts toward mutuality because of their different personalities and experiences. Applying the analytical framework helps understand how the context of dementia shapes the couples' efforts toward of mutuality. Recognizing difficulty in shared understanding can lead to discerning aspects of the interaction in which one spouse is preserving or mending their mutuality.



### **Shaping Mutuality Toward Accomplishing Life Together**

Understanding the intimate couples' efforts toward mutuality involves analyzing aspects of language reflecting the relational in the interaction. Tolhurst et al. (2017) state that "a socially framed understanding of dementia requires "a cogent empirical platform at the level of experience and immediate relationship" (p. 214, 2018). The analytical framework developed in my study provides such a framework. It leads to identifying how the intimate couples' responses (familiar and unfamiliar selves) and their style of interaction shape their mutuality.

Manifestations of dementia in the interaction include the broader social and medicalized perspective of dementia and the neurological changes associated with dementia. There is interplay between these manifestations of dementia, each spouse's agency, the couple's past relational history, and other aspects of the couple's life together contribute to shape the intimate couples mutuality and how they accomplish life together.

Responses in interactions of couples living with dementia illustrate efforts toward mutuality: they express interest in their bond with each other and in establishing a shared understanding. The context of dementia alters established ways of interacting and accomplishing everyday activities. Couples continue to seek shared understanding as they adjust and develop new approaches to their life together. The findings of this study illustrate that the patterns of responses are, however, shifting and in flux, as each partner tries to make sense of their self and relational identities in a changing dementia context.

The following excerpts demonstrate how the application of the analytical framework leads to discerning how the context of dementia shapes the couples' efforts toward mutuality. It also suggests that in their adjustment to dementia the couple shape a mutuality which is an aspect of how they accomplish life together.

**Paul and Elizabeth**

Six different excerpts from the joint interviews and an individual interview with Paul and Elizabeth illustrate the fluctuating and dynamic interactions reflecting maintaining, disrupting, and enhancing processes that combine to potentially shape their sense of mutuality. Some of the responses suggest their response to the medicalized perspective of dementia.

An interaction illustrating maintaining between Paul and Elizabeth occurred at the beginning of the joint interview in the first field visit as I collected demographic information from the two of them:

- Researcher:** *So how long have you been married?*  
**Paul:** *(Chuckle) Well we're approaching 50 (chuckle).*  
**Elizabeth:** *Fifty-two.*  
**Paul:** *Fifty-two?*  
**Elizabeth:** *Fifty-two years.*  
**Paul:** *Elizabeth will say it's a real challenge (chuckle).*  
**Elizabeth:** *So will you.*

The dynamics of the interaction illustrate a complexity of responses that ultimately preserves a shared understanding about the nature of their relationship. There is some tension created in this initial interaction-- first by Elizabeth correcting Paul, then by Paul stating they have a challenging relationship. Usually a 50<sup>th</sup> wedding anniversary is a milestone that people recall. Therefore, Elizabeth's correction of Paul is a reasonable response, but does not consider the implications of this small correction for Paul. Paul's comment ("Elizabeth would say it has been a challenge") may reflect his sensitivity to the social situation. Paul may also be interpreting Elizabeth's response as critical of his difficulties. His response distances himself from her by talking about her in the third person and by bringing up the idea that their relationship is challenging. Elizabeth may feel criticized by his forgetting this important information and by implying that she believes the relationship was challenging in front of the interviewer during the

first interview. Elizabeth's retort (that he would also say they have a challenging relationship) contextualizes their relational experience beyond the more recent context of the diagnosis of dementia. They are not 'the couple with dementia', rather they are a couple who live with a challenging relationship (preserving shared understanding).

In another excerpt, Elizabeth and Paul are responding to a medicalized understanding of dementia. Paul is upset that Elizabeth tells him to 'look at the calendar' for information on the day and what is happening on that day. She explains that the doctor told her to tell Paul to read the calendar rather than ask her what day it is. Elizabeth responds to the losses by trying to do what the doctor says, rather than considering the impact of responding to Paul in this way. Elizabeth's response to Paul may punctuate his awareness of loss. Paul notices how things have changed and this causes disruption in their interaction. The following interactions suggest that Elizabeth is mending her understanding of her husband's response to the interaction:

**Elizabeth:** *But the doctor has said, Paul should have a spot where he puts his keys, his, his glasses, his, anything that's important, one spot that he goes to. And he should have a place where he reads the date and the month and the day of the week. And I put it up on a big chart on the wall for a while but he didn't seem to, it didn't seem to be something...*

**Researcher:** *It seemed artificial.*

**Elizabeth:** *Yeah.*

**Paul:** *You're right on, you're right on.*

**Researcher:** *...it's just like, yeah so you're creating something different from the way it was before....*

**Elizabeth:** *Almost like a, a demeaning. I felt it was kind of demeaning.*

**Paul:** *Absolutely. Absolutely. That's, that's how I feel, she's demeaning me. You know but oh it hurts, it hurts so much, she doesn't know how much it hurts me because if she did she wouldn't do it.*

Previously it was understood that Elizabeth would help Paul by listening to him and answering his questions. When Elizabeth does not help him, Paul expresses how he is hurt by their interaction. Elizabeth makes an important effort to understand his emotions and reframe

their interactional dynamics (toward shared understanding). Paul makes it clear that he wants his interactions with Elizabeth to be recognizable (the way they were before). Her responses, based on the doctor's advice on how to respond to Paul's forgetfulness, had unforeseen consequences on their everyday activity. Paul's ability to articulate his difficulty prompted Elizabeth's reflection.

Mending is exemplified when both Paul and Elizabeth agree on a common interpretation of some difficulty in their shared understanding, in the next excerpt:

**Paul:** *I was going to mention the one thing and it's a negative thing. The thing that bothers me the most and has surprised me, you know I like to think I can handle anything and everything that comes, but the thing that has bothered me the most is my relationship with "Elizabeth" and that she doesn't appreciate, I'm a pain in the butt for her for, for telling this and, and I know it. And it creates some, that's the only place I know where I get angry at my wife is the frustration and...*

**Elizabeth:** *His, his.*

**Paul:** *My frustration.*

**Researcher:** *Yeah?*

**Paul:** *Yeah. You know I've, I've never talked angry to her, I do that. But you know married 50 some years, you know I would say 50 years, I never swear at "Elizabeth", I would never shout at her, I would never scream at her, you know, now I have to hold things back and sometimes some slip out a little bit you know. And I don't feel good about it.*

**Elizabeth:** *Yeah, there's some personality change.*

**Paul:** *Yeah, yeah I would say that's the one personality change that I know that's happened to me.*

Paul describes his own responsibility for expressing frustration and may feel shame when talking about his loss of control. Elizabeth tries to reduce Paul's shame by identifying dementia as a mitigating circumstance. This response might also represent a reframing on her part in order to manage her own emotional responses (e.g., to not take it personally). Paul's ultimate agreement with her interpretation (that he has had some personality changes related to the dementia) may serve to mend mutuality. However, mutuality that fosters the losses of dementia

may lead to an isolated experience for couples as they may experience a shared understanding about the futility of the adjustments each makes to their situation.

A disrupting interaction between Paul and Elizabeth is exemplified when the couple's responses suggest polarity in their understanding. Paul and Elizabeth's comments underline difficulty with their shared understanding:

**Elizabeth:** *And my biggest challenge is Paul can't see anything but himself.*

**Paul:** *And he does what?*

**Elizabeth:** *You can't see anything but yourself. He's the focus of his, his world and his world is not beyond that.*

**Researcher:** *It's changed that way for him.*

**Elizabeth:** *Yes, yes. And, and so it's, it's hard when there's someone there that's not really there other than they're viewing the world just, just all about themselves. And it, it's tough. It's tough when, so it's a...*

**Paul:** *I don't but no we're serious, I will stay serious, I brought it up because that's my biggest issue is my wife, I haven't asked if my wife agrees with me but.*

Elizabeth describes how Paul's behaviour is focused primarily on himself ("You can't see anything but yourself. He's the focus of his, his world and his world is not beyond that"). Paul states "my biggest issue is my wife" indicating the significance of his relationship to his understanding of the problems he is having right now. They both express their own need to be understood as the unfolding of the day-to-day creates a rift in their experiences.

Individual interviews may provide the venue for the spouse to reflect and mend their recognition of the meaning of Paul's behaviour within an interaction. In this excerpt Elizabeth reconsiders Paul's behaviour and how it reflects his current difficulty in the context of dementia:

**Elizabeth:** *Well I kind of, that's what I try to do, I, I like him to feel, you know cause I, as a capable individual, yeah and I know he wants to be a capable individual. And what he can be capable in doing gets less and less and less and less. And he realizes it. And he's very good of accepting it. He doesn't like it always, but realizes where he's at.*

**Researcher:** *Um-hmm. Are you, are you finding you're dealing, like compared to what you used to, is there more anger from him than there used to be?*

**Elizabeth:** *Paul was very easygoing, very, very seldom did he get angry. Now he'll have a short fuse and it's frustration that's all, but it's a short fuse; but it's very quick and over. It's, he doesn't hold a resentment or, but it will be the same fuse over and over. You know he might want to get up at 6:30. And we sleep till quarter to seven, well that would make him angry cause now we're not on time and we're not you know, and then the next day we sleep in, it will be the same, you know the same incident will trigger.*

**Researcher:** *He won't adjust to it.*

**Elizabeth:** *No.*

**Researcher:** *No. To a change.*

**Elizabeth:** *No.*

This interaction exemplifies the process of mending (maintaining); the process of clarifying the nature of the problem of Paul's "small eruptions" in response to rising late as related to his dementia.

Enhancing processes are also evident in the next excerpt of Paul and Elizabeth as they attend to those aspects of their everyday activity that have not changed. The interaction in this next excerpt occurs as Paul and Elizabeth respond to a question about their activity of going for a work-out every morning. Although physical and cognitive changes have impacted their experience of this activity, they focus on recognizable aspects of the activity, particularly since it is something they have done together:

**Researcher:** *And I just wanted to talk about that activity that you did together. And I wanted to find out like how long have you been doing that activity and interested in that 'cause I think that's a very nice activity that you do together (chuckle), thirty years.*

**Paul:** *For years.*

**Researcher:** *Thirty years hey wow.*

**Paul:** *Yeah, yeah.*

**Researcher:** *Yeah and so do you both, like when you go there do you run and you do weights?*

**Elizabeth:** *It's evolved over the years. Paul used to do a lot of jogging but he has spinal stenosis which makes his back that he can't jog anymore. He, he's limited to what machines he can go on. And he swims and so we each do our own thing. We get there and you separate as he goes to the men's locker and I go to the lady's and then we meet again at the end. Now we may see each other, he might be jogging while I'm on an elliptical machine or we might be doing weights. It depends, we don't work out together, but we...*

**Paul:** *No, we see each other.*

**Elizabeth:** *Yeah.*

**Paul:** *We see each other a lot of times when we're working out you know. And she comes with me, I'm really happy that she's coming with me. I hope she's happy.*

**Elizabeth:** *Yeah, I'm happy that you're there.*

**Paul:** *How many people at my age would get up at 5:00 in the morning to go and work out? And I love it.*

The couple defines their exercising positively, agreeing that they make each other happy, and they converse in a back and forth in an inclusive manner. In both the describing of the activity of going to the gym in the morning, and in the immediacy of the interaction, the interaction may be enhancing their sense of mutuality. In the interaction, the couple indicates that their shared activity has not changed for the 30 years that they have engaged in this activity. In an earlier interaction, Elizabeth stated that Paul needed help when there were changes in the layout of the gym. The interaction conveys a shared understanding in this activity that demonstrates the couple's strength in living within the context of dementia.

The most common processes identified in Paul and Elizabeth's interactions reflect maintaining. Through preserving and mending, they maintain their sense of mutuality and connectedness. In disrupting processes, shared understanding of the meaning and impact of dementia is threatened. This is reflected, for example, in the individual interview when Elizabeth interprets her husband's behaviour as being critical of her; later, however, she is mending or maintaining mutuality by framing her husband's responses as "small eruptions."

The application of the analytical framework leads to considering how the intimate couple responds to the dementia context (e.g., changing abilities and responses, perception of dementia). The application of the analytical framework highlights Paul's continued ability both to mend and to preserve interactions and helps to identify how common perceptions about dementia shape the couple's interaction. This is exemplified in the couple's common agreement that the changes in

Paul's behaviour are related to dementia. The couple's response to dementia shapes their interactions and shapes their mutuality. Moving towards a mutuality that fosters the couple's bond includes identifying positive shared understanding in their interaction (e.g., through the capacity to preserve and mend).

### **Tom and Mary**

The dynamics of the interactions between Tom and Mary are a window into the struggles that Mary is having with the diagnosis of dementia. Three different excerpts of both joint and individual interviews illustrate how Mary's mending is expressed in responses and may reflect the process of changing dynamics that occur in the interaction.

Mary's worry was so significant that there were also a few times, when the tape recorder was off, that the couple was clearly having moments of tension or having difficulty with their shared understanding (documented in field notes). Mary expresses her worry and concern about the implications of dementia for her husband by asking me about resources that are available, developing her own support group and attending programs meant to support the person with dementia and their spouse. Her concerns were not entirely addressed in the current programming available. In the joint and individual interviews, Tom also notably describes disrupting interactions between him and Mary. For instance, Tom interjected a comment about his frustration in amongst the descriptions of recollections that conveyed his admiration for his wife.

**Tom:** *Yeah. I'll tell you a little story, quick one. I was in the Middle East with the United Nations and I got a phone call, oh your wife phoned. So I wandered out to the commons group and I said to her on the phone, how's the kids she said I bought a house, I said oh that's nice and I'm walking back to the office and she just told me she bought a house, so I turned around, you bought a house, yeah she said.*

**Mary:** *I need your signature.*

**Tom:** *On Blackwood St.*

**Mary:** *Yeah.*

**Tom:** *So I said: well, how did you do it?*

**Mary:** *I need your signature, yeah.*



**Tom:** *She said don't worry about it, it's all done.*

**Mary:** *(Chuckle)*

**Tom:** *Simple as that. So...I've never had the problem with that sort of thing with my darling wife.*

Near the end of the excerpt, Tom attempts to preserve recollection of the 'good decisions' his wife made in the past.

A similar interaction occurs later in the interview. Just prior to this next excerpt, Mary and Tom were illustrating enhancing interactions, when discussing grocery shopping. Tom interrupts this discussion to voice his concern regarding Mary's responses to him moving about in the house.

**Mary:** *When we go out, we choose our times now and when you're retired you can do that kind of thing.*

**Researcher:** *Yeah, you're a little more flexible (chuckle).*

**Mary:** *Yeah.*

**Tom:** *The frustration is coming up the stairs at 7:00 and putting the kettle on and poor old Mary, when she gets startled she explodes.*

**Researcher:** *And you're trying, and you're trying to do your best, and you can't seem to avoid that, yeah.*

**Tom:** *Yeah, I can't seem to accommodate, accommodate that, that sneaky trying to get by without the burglar coming in.*

Verbal interchanges between Mary and Tom in the immediacy of the interaction primarily suggested preserving and/or mending processes. When Tom described difficult events, Mary usually agreed or did not say anything. Mending (maintaining) is also identified in the last individual interview with Mary. In this exchange with the interviewer, Mary reflected on her own process demonstrating the detail of mending of her understanding of dementia. Her initial responses to dementia as suggested in the description of the disrupting interactions suggested her medicalized perspective that is being changed in the process of everyday interaction:

**Mary:** *I was angry because I was selfish, totally selfish when I think about it. Why me, Lord, why has he had six extra years of life that I'm not having because he's six years older than me? I want to have those years before I'm at his age and have to set*

*down roots and not travel anymore. Why is it happening to me? I still have a life, I still want to do what I want to do, still want to travel and that's, that's the selfishness coming out, yeah.*

**Researcher:** *It's kind of a natural process though.*

**Mary:** *I understand it is, but I mean you still feel guilty afterwards. But I guess you learn the process, you learn as you go along don't you. I made life kind of miserable for both of us actually, I wasn't very nice.... and I had a profound respect for those ladies who I know their husbands aren't as highly functional as mine. So it really brought me, brought it home, how grateful I am that I have all this information at my fingertips and here I can utilize that to help him and the anger subsided and acceptance ensued. And now I realize we can have a very nice life together. There are lots of things we can't do, can't go away for instance together for three months; he still doesn't want to go down to Florida even though physically I believe he could.*

In this interaction, Mary describes how the diagnosis of dementia was associated with losses. She engages in mending to maintain her sense of mutuality with her husband. She describes, explains, and tries to understand her own responses (which she evaluates critically as selfish, angry and not nice). She recognizes her difficulty with anticipatory loss yet maintains hope that they can still have “a very nice life together.”

Analysis of Tom and Mary's interactions identified uncertainty and loss as a significant aspect of the context of dementia threatening their mutuality as a couple. Mary's anticipated loss (increased concern about the future) related to dementia and intense vigilance and emotionality (“explosions”) reflect uncertainty in that increases difficulty in the couple's mutuality. Mary experiences a loss because she understands that Tom's lack of interest in travel is related to his dementia. She anticipates further losses in their shared understanding and shared life together. The application of the analytical framework directs attention to those aspects of the context of dementia that shape both a positive movement towards increased shared understanding, as well as difficulty in shared understanding. In this case, the application also identifies the unfolding nature of the context of dementia for the intimate couple.

### Sam and Roberta

Describing the fluctuations in Sam and Roberta's interactions involves two excerpts. In the first, the concerns are related to significant changes in everyday activities related to Sam's dementia. Roberta's vigilance is explicitly related to concerns of safety and ensuring tasks are complete than concerns of loss of mutuality with her husband. In the second excerpt, Roberta takes a step back from her practical concerns and considers the long term implications of dementia on her mutuality with her husband.

In response to questions about how everyday activities had changed or not changed for the couple in the last few years Roberta leads the conversation:

**Roberta:** *So the big change is he's not driving. And so that's...*

**Sam:** *Yeah, I mean they sort of said you know you might want to turn in your driver's license and Roberta thought that was a great idea and so I thought I couldn't argue.*

**Roberta:** *You know the physician said that you know she's responsible if he has an accident and therefore...*

**Sam:** *Yeah, that was, that was the main push.*

**Roberta:** *...you know it would not be wise for him to be driving and he'd had two accidents prior to his diagnosis.*

**Sam:** *Yeah, but that was a long, long, time before.*

**Roberta:** *So we sort of said, but that was you know a major thing, and I mean he still gets quite fussed when I'm driving because he likes to tell me what to do and how to do it.*

**Sam:** *Well, I more often irritate you by criticizing other driver's misbehaviours.*

**Roberta:** *That's correct, that's correct.*

**Sam:** *I don't criticize your driving much 'cause you're a darn good driver.*

**Roberta:** *But anyways so I think that, the driving is a major thing and, and the second major thing right now is that he used to be independent in terms of here's a job go do it but now he's not as reliable to do a job, so.*

**Researcher:** *He can still remember how to do the job but he gets distracted, is that what it is?(Talking to Roberta)*

**Roberta:** *Yeah, he gets distracted in, in terms of where the tools are and then after the job's finished, the tools can be anywhere but where they normally are. So it, yeah it's, it's, I finally decided just be beside him and work together, it just saves a lot of*

*frustration, so that's a major change in my books. He still cuts the grass independently and that's his main job at the cottage and here, but other than that.*

**Researcher:** *Um-hmm. You kind of keep a closer, like...*

**Roberta:** *And the, the other thing that happens now is that in the morning when we get up I'll just say, okay, this is what's happening today to sort of get him on. And, and he might not remember but you know if, if when it comes up again, he will say "oh yeah", so.*

**Researcher:** *So your major changes for you guys is that Roberta has to identify a job for you to do while before you used to do it on your own. .*

**Roberta:** *Yeah, yeah.*

**Researcher:** *Yeah. And, and keep him organized.*

**Roberta:** *I'm out in Beausejour two days a week babysitting; he's okay to be left for those, you know I'm gone in the morning and come back at supper and he, he's fine. I'll leave a list but he normally doesn't read the list, but you know I know he's okay, otherwise he can phone and say, what's, what's up, what should I be doing.*

**Sam:** *Yeah, I need, I need cues more than I ever had.*

In the first part of the interaction the couple lacks shared understanding about why Sam lost his driver's license (signaling disruption). However, Sam's responses convey an interest in maintaining, by agreeing with the decision to give up his license to make it easier on Roberta. Sam also maintains the interaction by preserving Roberta's role as the organizer in the family. Roberta's comment that Sam still gets quite 'fussed' when she is driving suggests some difficulty, but Sam re-interprets the reason for this; he enhances their shared understanding by explaining that he is fussed by other drivers; he comments on her good driving.

In the latter part of the interaction, Roberta starts referring to Sam in the third person, describing how his memory losses are experienced in day-to-day interaction. Although this may disrupt mutuality, Sam preserves the interaction by agreeing that he needs cuing. He endeavors to secure a shared understanding about their experience together. Roberta is faced with trying to mend those aspects of the current situation that are inconsistent with her previous way of relating with her husband.

As they describe changes in their day-to-day life, this couple highlights their context of dementia (e.g., Sam requires reminding and organizing but has other continued abilities that can make it more difficult for Roberta to impose changes necessary for his safety). A final excerpt occurred in the individual interview with Roberta. She describes how everyday life is intertwined with a sense of togetherness:

**Roberta:** *The only thing that I've sort of noticed which is new to me is that I realize this year going to the cottage, in the past I've always thought to myself well you know what if, if he were institutionalized or whatever I'd still come to the cottage, not, not anymore, like it just sort of came to me like you know if he's not here I don't, I don't want to be here. Which, which for me was, was sort of major, I just sort of whoa, okay.*

**Researcher:** *Yeah, 'cause this place is associated with him.*

**Roberta:** *Yeah, yeah so it was sort of interesting.*

As with, Mary and Elizabeth, the individual interview is an opportunity for Roberta to collect her thoughts about her current circumstances and voice her ongoing interest in having a mutuality that supports her life long bond with her husband. While the practicalities of keeping life organized redirects Roberta's attention of shared understanding with her husband, her reflections identify how she mends the difficulties of daily life. She is mending her current experiences (re-organizing everyday activities, the diagnosis of dementia and symptoms of dementia).

These two excerpts from Sam and Roberta exemplify the preserving and mending processes that occur as couples maintain a sense of togetherness in the face of day-to-day uncertainty. Balancing safety concerns with driving independence, or even leaving the person with dementia alone can deter from a sense of mutuality, but these issues are complex. Sam retains some continued abilities, yet there is uncertainty. The analytical framework allows for an understanding of the relationship which acknowledges this interplay as couples seek to balance mutuality within the changing context of dementia.

### Peter and Ruth

In the next four excerpts, Ruth and Peter demonstrate how they attend to each other's responses. Peter may have difficulty remembering, but he continues to show agency in wanting to sustain his sense of mutuality with his wife. Ruth's attention to Peter is suggested in the way she adjusts her responses accordingly to mend disruptions that occur when Peter's changing abilities become too much the focus of the talk:

**Ruth:** *He doesn't do the things that he would have done, like he would have taken the garbage out and he would clean up after the dog in the backyard and things like that, where he doesn't, he, he will do it if I go out there with him and do it with him.*

**Researcher:** *Okay.*

**Ruth:** *But for him to do it by himself, no he doesn't do it. And, well, you don't get dressed by yourself anymore either. I have to help you with that. And the food, the food always had to be put on the table anyway, yeah.*

**Researcher:** *Okay.*

**Peter:** *And you always had to tell me what to put on for clothing, right.*

**Ruth:** *Yeah. (chuckle)*

Ruth describes how everyday activities have changed for her and Peter. Within the dementia context, Peter does not participate in many of the everyday tasks he used to. Yet both Peter and Ruth appear to be preserving his understanding of their previous relationship and the division of labour and gender roles. For Peter, this may have been a way to advocate for himself. This softens their sense of the ways that the dementia has altered their typical patterns of relating to each other, something that is disrupted as Ruth initially talks about Peter's inability to continue in some of his traditional tasks. In this maintaining interaction, Peter preserves a memory that Ruth always helped in in some way with dressing. Ruth's response mends any difficulty in shared understanding that they might have had in a discussion of how Peter no longer can help.

Other interactions highlight the significance of Ruth's ongoing social network in their current context of dementia. In the following two enhancing interactions, Peter and Ruth are

responding to the photographs I had taken of them. In the first excerpt, Peter is looking at a photograph of Ruth talking on the phone. They describe what they understand is occurring in the photograph:

**Ruth:** *Yeah. I was on the phone because I was getting ready to go up to Birch River.*

**Peter:** *Birch River.*

**Ruth:** *Yeah.*

**Peter:** *Did I go with you with you to Birch River?*

**Ruth:** *Yes. You needed to come so that you can get the coffee while I stand at our craft table.*

In another excerpt the couple is looking at a photograph of Ruth answering the door. In the photograph Peter is holding onto their dog while she paid someone at the door:

**Ruth:** *This is when my Avon lady came and I had to write a cheque for her.*

**Researcher:** *Wasn't it a fur coat that was being delivered?*

**Ruth:** *Oh my fur coat, yes (chuckle).*

**Researcher:** *And, and what were you doing Peter?*

**Peter:** *I don't know.*

**Ruth:** *Chasing the dog, and hanging onto the dog so he wouldn't go out (chuckle).*

In both interactions, questions asked about the photographs elicited descriptions of the couple being helpful to each other in a shared activity. The enhancing styles of interaction connect the shared activity depicted in the photograph and their shared activity of discussing the photograph. In the interaction, Ruth makes positive statements about Peter's helpfulness. The context of dementia continues to surface in Peter's forgetfulness, yet Ruth supports his continued contribution.

In another enhancing interaction Ruth has just been talking on the phone. Peter is interested in what is happening in Ruth's life:

**Peter:** *Who was that?*

**Ruth:** *Well all that extra material I got that I got from the Gates woman in Treherne that I didn't use for the quilts at Christmastime well then, all the, one of the ladies from the shop, her church makes quilts for World something. Anyway I'm going to donate all that*

*extra material that's hanging around here to them to make quilts for, to give away to World, what did she say.*

**Peter:** *If they give them away, if they give them away, where will they go...*

**Ruth:** *World Vision I think. So anyway, it goes, goes to people that need them.*

**Peter:** *Well I'm glad to see that. It is because those people, those people don't have the money so give them something.*

**Ruth:** *Yeah that way, 'cause I've got, yeah, I've got lots of material that's been donated to me that I can never use, so there's just no way I can make that many quilts (chuckle) by myself.*

Peter's continued engagement in everyday life is illustrated in the questions he asks Ruth about her phone call. Ruth and Peter also share a common value system represented in this discussion. Ruth's responses identify her continued interest in being engaged with him. Peter may have memory loss, but is sensitive to the subtleties of social interaction. He engages in activity that reinforces his shared life with his wife.

The excerpts from Peter and Ruth illustrate the significance of their relationship within the context of dementia. In the first excerpt, Peter ensures his voice is heard in the discussion, and links current activities to his sense of the past. Enhancing interactions were evident when Ruth identified how Peter has been helpful (reinforcing a sense of appreciation).

Description of the couple's responses and their interactional style manifests the relational approach by bringing attention to how responses and interactions are changing in the context of dementia. Salient features of Peter and Ruth's situation such as the symptoms of dementia, most significantly memory loss, increase Peter's uncertainty within the interaction. Ruth and Peter's capacity to recognize and preserve their interaction is evident in their style of interaction. Common values, shared activities and a common life together foster their mutuality. The intimate couple makes efforts toward mutuality that secures their bond and their ongoing ability to accomplish life together.



**Emmanuel and Karen**

Two excerpts exemplify interactions in which Emmanuel and Karen identify how their sense of mutuality has changed, but nonetheless continues to be present. In interviews, Karen describes the experience of getting the diagnosis, the symptoms of dementia and the responses to these symptoms. In these descriptions, Karen maintains her interaction with her husband by conversing about the situation in an inclusive manner. However, Emmanuel's verbal absence from the interaction is evident. As dementia progresses, Karen tells the story of their relationship, carrying it to others and as she may be reinforcing who she knows she is in relationship with her husband.

This first excerpt is an example of how the couple's everyday activities have changed, in that they no longer go to the cottage alone. Karen allows others to help her with Emmanuel's symptoms:

**Karen:** *We used to go out to the cottage together, alone, but now we don't go unless the children are there to help with the car, because we don't have the homecare when we go out there.*

**Researcher:** *So the, the children help with the dressing and undressing when you go to the cottage.*

**Karen:** *Yeah, and it's the incontinence has been the main issue. So that's, you know that's always a biggie.*

**Researcher:** *When did that start?*

**Karen:** *Ooh, well we were already kind of watching ourselves before those two trips last year in January. So it's, and it's, it's accelerated. It's pretty at the high water mark I would say, I don't know how it could get any... (field notes identify that Karen appears uncomfortable with the description of this line of talk in front of her husband)*

In this excerpt, Karen responds to questions about how the couple's everyday activity has changed and she includes her husband, although he is unable to contribute facts to the description. She is uncomfortable discussing personal details (incontinence) in front of her

husband and me. This may be in part because talking about this may also be drawing attention to the decline her husband is experiencing.

In another excerpt, Karen is talking to Emmanuel about his move to a personal care home.

- Karen:** *So, but if you live there at night, I'm going to come in the day, right.*  
**Emmanuel:** *Yeah, but how will you feel if you go there yourself?*  
**Karen:** *Well, I'll feel great because you're going to be there.*  
**Emmanuel:** *Well that would mean that you'll spend a considerable amount of time...*  
**Karen:** *With you.*

This is an enhancing interaction. Emmanuel and Karen are conversing with each other and both are following the topic. In this excerpt, Emmanuel demonstrates an understanding of a fairly complex situation. His understanding is directed towards his wife and how she will cope. Emmanuel indicates his concern about her potentially being alone and Karen interjects quickly and redirects the conversation to being together.

### **Summary of Shaping Mutuality Toward Accomplishing Life Together**

Applying the analytical framework can help discern how the intimate couple shapes their mutuality in the context of the changing circumstances of dementia. The couples shape their mutuality to continue to accomplish their life together.

The analytical framework directs attention to how symptoms of dementia, the declining verbal ability and memory infringe on shared stories and activities. It also directs attention to the capacity of each partner to preserve and to mend to maintain the interaction. Although these couples can have increased difficulty in their shared understanding, as articulated through stories and events, their mutuality is reinforced and reflected in their mutual awareness of each other within the interaction. The significance and interest of both spouses in maintaining a sense of togetherness is also evident.

Exemplars from different couples have been used to explore how interactional processes are shaped by the context of dementia, and how these processes shape mutuality and help the couple to continue to accomplish life together.

Styles of interacting are connected to shared understandings about self, each other, and the relationship, often expressed in relation to shared activity. Although disrupting processes signify difficulty in mutuality, mending and preserving strive to maintain mutuality and an ongoing sense of connectedness as a couple.

### **Summary of Chapter 5**

In this study, the application of focused ethnographic method to explore a relational approach highlights how mutuality is established in shared activities, values, and social connections in the context of dementia. Learning from the couple was based on engaging them in their natural environment, facilitating opportunities that could promote the couples' mutual engagement and the researcher's engagement as a participant observer. The analytical framework provided a logical approach to recognize how the context of dementia was shaping their mutuality. For example, changes in memory can limit sharing of certain stories or the specifics of stories. Mutuality occurs as each spouse attends to the other. Mutuality is exemplified when a spouse attends to the content of the story by asking for clarification or by recognizing and responding to other details of the story. The responses and the differing styles of each spouse are shaped by the dementia context, and in turn shape shared understanding and mutuality. The application of the analytical framework identifies how responses to the social understanding of dementia also shape the mutuality of the couple.

Chapter 5 has described how research question 2 was answered. The responses of the intimate couple form a pattern that express shared understanding or mutuality in the interaction.

These are described as styles of interaction and are identified as disrupting, maintaining and enhancing. Examples of the styles of interactions illustrate both the style of interaction and those aspects of the context of dementia that influence the expression of mutuality between the couple. Research question 2 is also answered by providing excerpts that illustrate that the dynamics of the styles of interaction shape the couple's life together. The analytical framework was applied to several intimate couples' interactions to illustrate how the couples adjusted to the context of dementia and shaped their mutuality towards accomplishing a life together.

## **Chapter 6**

### **Discussion of Findings**

My study exploring efforts toward mutuality of intimate couples living with dementia grew out of my 35 years of clinical practice as a nurse, primarily with older adults and their families. In my nursing practice as a general duty nurse, nurse manager, supervisor, clinical nurse specialist, and educator, it was clear that the experience of living with dementia was not about the "patient", "client" or "person"; it was about the person and their family, friends, and others who were part of that ongoing experience. It was also clear that persons living with dementia (PLWD) and the people around them were active participants, seeking to make sense of themselves, each other and their circumstances in the context of dementia.

As part of a community based geriatric team, I assessed persons living in their homes, often couples, where one spouse was diagnosed with dementia and the other, was cognitively well. The dualism of separate assessment of the PLWD and the spouse caregiver to determine services and programs that met the unmet needs of PLWD and alleviated the "burden" of the caregiver did not provide a realistic picture of the family's situation. During these home visits, I observed couples who were struggling, trying to connect their past lives with their current circumstances, and who were accomplishing a life together although altered and not ideal from their perspective. I observed spouses connecting and disconnecting with each other in the dynamics of interaction around ordinary things like what to do in a day and extraordinary things like deep changes in roles and responsibilities. I believed that there must be a more wholistic approach to understanding the experience of the relationship that would illuminate how intimate couples were living in their context of dementia.

The literature that reported studies of "couples" living with dementia was scant when I started my study and it has grown, and my study will contribute to this body of literature. In

developing my research questions, I drew on my nursing practice and observations, asking about the couple's responses, interactions, activities, and connections. Because relationships are dynamic, I was interested in studying how the intimate couple actively shaped their connections, their mutual understanding of what the other was experiencing, and their mutuality as a couple. So, my research questions reflected my observations and perspectives.

1. How do intimate couples within the context of dementia respond to each other:
  - a) while discussing everyday activities and describing their relational story; and
  - b) while interacting during routine activities and novel activities?
2. How do the responses of the intimate couple shape their mutuality as a couple within the context of dementia?

My study fit with the current literature and will assist in a better understanding of couples living with dementia. It challenged the medicalization of dementia and the narrow clinical perspective of the caregiver-care receiver dualism. It explored the links between self, other and being a couple, focusing on efforts toward mutuality within the context of dementia. My study developed an analytical framework that attends to a couple's individual responses within interaction, creating the concepts of the familiar self and unfamiliar self. My study developed "themes" of the styles of interaction: enhancing, maintaining and disrupting.

### **Medicalization, Stigma, and Interaction**

Studies taking a relational approach have described how medicalization and stigma influence interactions occurring with the PLWD (Kitwood, 1997; McParland, Kelly, & Innes, 2017). Medicalization was described as leading to interactions that focused on the losses experienced by the PLWD (Kitwood & Bredin, 1992). The PLWD experienced stigmatization in the interaction which lead to excess disability or symptoms that was more than would be expected from their level of dementia (Castillo, 2011). Couples living in this medicalized and stigmatized world of dementia expressed a joint loss of personhood or a sense of being

"powerless over the disease" (Seaman, 2018, p. 68; Svanstrom & Dahlberg, 2004). Studies also described how intimate couples can reject the "master status" of the diagnosis of dementia (Beard, Sakhtah, Imse, & Galvin, 2012).

Overcoming the diagnosis of dementia means interactions in which the personhood of the PLWD is respected (Kitwood, 1997). The personhood concept has been applied to some studies to analyze whether or not the carer is bestowed personhood on the PLWD (Adams & Gardiner, 2005; Smebye & Kirkevold, 2013; Tolhurst et al., 2017). When personhood was bestowed, the PLWD was enabled to fulfill potential and to participate fully as a person. When personhood was not bestowed, the PLWD was disabled and deemed incapable of participation. The concept of personhood was "radically humanizing" (Forbat, 2003) because it recognized the significance of interaction on the PLWD. In the interaction, the PLWD can be the "PERSON living with dementia" rather than the "person living with DEMENTIA."

In their study, Johnston and Terp (2015) identified the potential for personhood within interaction when couples have information and support to process the diagnosis of dementia. In their study, they identified that some intimate couples experienced increased conflict in their relationship associated with being provided scant information at the time of diagnosis. They described that after diagnosis there was increased anger expressed within the couple related to a medicalized and stigmatized understanding of dementia. A similar response was evident in my study. The intimate couple, Mary and Tom, described Mary's uncharacteristic emotional outbursts since Tom was diagnosed with dementia. For Tom and Mary, medicalization might have exacerbated the experience of ambiguous loss because of its focus on the decline of the PLWD (Frank, 2008). The analytical framework that I developed identified Mary's response of the unfamiliar self in her current circumstances. The significant impact of her experience of

ambiguous loss on the interactions with her husband exemplified how the medicalization of dementia impacted the interaction.

Analyzing if the carers were conferring personhood on the PLWD may miss the significant influence of the back and forth interaction on the couple's experiences. Indeed, conferring personhood placed authority on the carer to grant personhood status rather than recognizing the agency of the PLWD. Taking a relational approach, the findings from my study identified the agency of both the spouse and the PLWD within their interaction. My findings suggested that the PLWD can exert agency within interaction and participate as a person. For example, Evelyn's response to John's description of her memory problems was that she "was not always like this" presented her agency to voice who she is as a person not just as a living with dementia.

In my study, the agency of the PLWD was expressed in responses suggesting their awareness of the stigmatized context of dementia. This is similar to other studies that suggested sense making in the narrative of the PLWD that reflected their awareness of the stigma of dementia (Beard et al., 2012; MacRae, 2010; Macquarrie, 2005; Patterson, Clarke, Wolverson, & Moniz-Cook, 2018). Their awareness was exemplified in my study in their interactions with the spouse when the PLWD had not acknowledged dementia or minimized the impact of their short term memory loss on everyday activities (Tom and Mary); when one explicitly tried to overcome the possible mistakes they could made in social situations (Sam and Roberta); in their self-depreciating remarks related to changes in their memory (Peter and Ruth); by emphasizing the terribleness of the disease (Paul and Elizabeth) or in thinking about medically assisted suicide (Harold and Alice).



Agency is the deliberate activity in which the PLWD maintained their personhood and their relationships (Boyle, 2014). As the PLWD lost their ability to communicate articulately, it was important to recognize their ability to act "intersubjectively, engage relationally and exercise influence" (Boyle, 2014) p.1135. It was suggested that agency is expressed in the interaction when PLWD express themselves and involve their seeking to be engaged in tasks that are relevant and meaningful to them (Boyle, 2017; Hellström, Eriksson, & Sandberg, 2015). My study identified that medicalization and stigmatization of dementia continued to influence the relationship of the intimate couple. In some instances, the PLWD and the spouse expressed a distancing in their relationship related to the stigma of dementia. In my study, the agency of the PLWD and their spouse have resulted in their continuing attention to the other and suggest how they overcame the stigma of dementia in the interaction. As discussed by Boyle (2014): "Agency is the way the subjective self becomes the social self" (p. 1131). The analytical framework developed (responses of the familiar and unfamiliar self and styles of interaction) in my study can be applied to how the broader social implications of having dementia might influence the intimate couple's interactions and how their social selves manifest their responses to the medicalization and stigma of dementia.

### **Linking Self to the Couple**

Symbolic Interactionism (SI) postulates that the social self is created and reinforced in the interaction (Caddell & Clare, 2010). My findings fit with research that described how the social self of the PLWD and their spouse were being reinforced and created in the interaction (Hellström, Nolan & Lundh, 2005).

The understanding of how the social self is represented in talk is dependent on how self is conceptualized in the interaction (Caddell & Clare, 2010). My study identified that the PLWD

and their spouses reinforced who they were in the interaction and responded to each other's claims about who they were. At times, the couples both reinforced themselves and the others and at other times refuted the other. The findings reflected that self exists in conjunction with others (Blumer & Morrione, 2004). The interplay of social selves was illuminated in an interaction between Josephine and Martin. In this interaction, Josephine, the spouse was describing her physical health problems. Martin, the PLWD failed to recognize the problems she was describing about herself. Martin over road Josephine's descriptions and reinforced what he knew of her; that she is a "people person".

Studies that discussed the social self of the PLWD highlight how PLWD were not lost but continued their ongoing commitment to others and their interactions with others (MacRae, 2010; Phinney, 2011). In my study, the PLWD established or reinforced their social self through agency and autonomy in everyday activity and in response to their interactions with their spouse. Agency was manifested when the PLWD described their previous roles and accomplishments and their current accomplishments. Roles associated with gender identity also exemplified how the PLWD reinforce their current self in relationship. Agency may be expressed when the PLWD continues to engage in traditional activity.

In the context of dementia, agency may be expressed when the PLWD continues to engage in tasks associated with traditional gender roles in their long term relationships. Opportunities to continue to engage in gender related roles were evident in the interaction of the intimate couple in my study as in others (Boyle, 2017; Keady & Nolan, 2003; Molyneaux et al., 2012). In my study, agency related to continuing gender related roles was exemplified in the consistency in which Evelyn (the only female PLWD) insisted on taking over the role of providing hospitality when we were engaged in having coffee together. This was also

exemplified in Sam's continuing to mow his lawn and his neighbours' lawn. PLWD sometimes resist giving up these traditional activities. This was exemplified in Elizabeth's story of Paul having a difficult time giving up doing taxes. Another story from Sam and Roberta described the difficulty of giving up driving. Hellström et al. (2007) described the difficulty that the PLWD has in giving up roles and described it as a gradual process of 'letting go.

The voice of PLWD was expressed when they interacted to support their own agency. This is identified in studies that described PLWD sense making as an effort to maintain their sense of self in response to their external world (Clarke et al., 2010; Hydén and Orulv, 2009; Merrick et al., 2016; Müller & Mok, 2014; Phinney, 2011; Westius et al., 2009). In my study, PLWD 'expressed their voice' in the interaction. The PLWD agency was evident in the interaction when they described past roles and accomplishments. Engagement in these roles was consistent with PLWD knowing who they were in relationship. It is also described in some studies as being important in reinforcing their position in their relationship (Purves, 2011).

Agency of the PLWD was suggested when they interjected comments into interactions that reinforced their presence in the story and in the interaction. At times the PLWD seemed to expressing their experience of the story being told and the way it was being expressed in the interaction. For example, Peter interjected into an interaction in which a relational story was being told by his wife. He asked his wife for further details related to the events in this story. While Peter could not participate in recollecting the exact event he could ensure a detailed telling by his wife that included his activities during these events. Harold interjected into a description of changes about everyday activity by talking about medically assisted suicide as a reasonable option for him. It seemed that he was voicing his experience of the discussion of his dementia and declining ability to do everyday activities. In both these different examples PLWD show

their agency or their interest in being engaged in the interaction. Spouses of PLWD responded to the agency expressed by the PLWD in the interaction. Like other studies described their responses suggested their attention or consideration of the PLWD as well as to the increasing demands of the context of dementia (Karner & Bobbitt-Zeher, 2005; O'Connor, 2007).

The changes that were encountered in everyday activity involved the spouse of the PLWD adjusting to increasing responsibilities as well as managing concerns that they were overstepping and decreasing the autonomy of the PLWD. For three couples, Paul and Elizabeth, Harold and Alice, and Peter and Ruth, agency was expressed by the PLWD interrupting their spouses' description of their increased responsibility related to dementia. Interactions between Paul and Elizabeth, and Harold and Alice suggested that the spouse experienced ambivalence about their experiences. Elizabeth and Alice had responses of the unfamiliar self, suggesting their unresolved self. On the other hand Ruth adjusted quickly in the interaction in recognition of Peter's responses as indicating his interest in having a shared understanding with his wife. For example, Peter expressed his agency by re-interrupting Ruth's description of how she helps him. When she said she dressed him now, he responded that she always helped him with his clothes. Ruth adjusted her talk and included his interpretation into the discussion. She reinforced Peter's sense of continuity and brought a sense of continuity to her social self in her response. The social self of the spouse of the PLWD responded both to the agency expressed by the PLWD and to their changing context of dementia (Davies, 2011; Fletcher, 2018; Karner & Bobbitt-Zeher, 2005; Walters, Oyeboode, & Riley, 2010).

Studies often described how spouses of PLWD live with much uncertainty related to the unpredictable nature of dementia (van Wijngaarden, van der Wedden, Henning, Komen & The, 2018). It is described in these studies that back and forth nature in which the spouses of PLWD

tried to deal with the realities of the changes in the social situation lead to a social self that struggled with the uncertainty of who they were and how they were in their relationship. This struggle was exemplified in a few interactions in my study. Mary, for example, became increasingly vigilant about Tom's behavior and what was happening in everyday activity. Alice described how Harold's responses to her taking over too much left her unsure about what to do or how to support the relationship. In my study, the uncertainty reflected in the interaction may reflect a sense of loss of the social self of the spouse of the PLWD that was discussed in other studies (Johnston & Terp, 2015; Karner and Bobbitt-Zeher, 2005). The spouse of the PLWD similar to the PLWD was not sure how they fit in their relationship or in how they understood themselves to be in relationship. The details of the interaction identified the competing concerns that occur in the everyday life of the spouses of the PLWD.

Accepting the role of carer of their spouse with dementia is described in different studies as being helpful or not helpful in dealing with the competing concerns in their context of dementia (Hellström et al., 2007; Molyneaux et al., 2012 O'Connor, 2007). Studies discussed that the spouse of the PLWD can intentionally avoid taking on the carer role or consider their increased responsibility as part of the marriage vows (Hellström et al.; Molyneaux et al.). Studies suggested that when the spouse developed a social role of being the carer for the PLWD they distanced themselves from their spouse (Bosco, Schneider, Coleston-Shields, Sousa & Orrell, 2018; Kitwood & Bredin, 1992; O'Connor; Seaman, 2018). O'Connor suggested the spouse benefits from taking on the carer role because acceptance of the role may help the spouse consider the value of developing self-care strategies. In yet another study, it was suggested that taking on the carer role infringed on the togetherness of the couple by bringing an "artificial distinction between self and other" (Jenkins, 2014, p.135). Studies also described the

interpretive nature of the carer role in which the carer acknowledged dementia and adjusted to their circumstances (Graham & Bassett, 2006; Perry, 2002). It is important to recognize the process involved in adjusting to the circumstances of dementia and not minimize the experience of dementia for the spouse of the PLWD.

McGovern (2011) discussed the significance of recognizing and fostering the positive experiences of dementia with the couple to reduce the possible negative implications of the carer role. The analytical framework of my study captured the shifting familiar and unfamiliar self or dynamics of the interaction that was caused by the increasing responsibility of the PLWD spouse in the context of dementia. In identifying the efforts toward mutuality that were expressed in the interaction, health care providers are alerted to the spouses need for support. The results of my study demonstrate that in some instances the process of interacting with their spouse with PLWD and with the researcher fostered a mending process in which they come to recognize the value of their ongoing relationship with their spouse. This was similar to van Wijngaarden et al. (2018) in which they identified that acceptance of the circumstances of dementia occurred when the carer expressed how they experienced purpose and meaning in their new relationship with their spouse.

Spouses of the PLWD are described as expressing their purpose and meaning in the interaction when they supported the autonomy and the agency of the PLWD (Beard et al., 2012; Molyneaux et al., 2012; Robinson, Clare, & Evans, 2005). Other studies described the significance of the spouses supporting the previous roles of the PLWD in the dementia journey (Atta-Konadu, Keller, & Daly, 2011; Hellström, Nolan & Lundh, 2005). In my study, the spouse of the PLWD supported the PLWD autonomy and agency. This was identified when the spouse engaged and supported and scaffolded stories initiated by the PLWD. In the interaction itself,

some spouses actively encouraged their PLWD to speak and supported their autonomy to do what they could in joint activities. The support and encouragement evidenced in the interactions of my study are similar to other studies that described spouses who provided a positive nurturing environment to support the threatened self of the PLWD (Clark et al., 2010; Hellström et al., 2007; MacRae, 2010). The ongoing engagement of the PLWD in activities and social interaction as discussed by Beard et al. (2012) fostered a sense of reciprocity important for the reinforcement of the social self of both the spouse and the PLWD.

Couplehood is a concept applied to describe how the intimate couple live within the context of dementia (LaFontaine & Oyode, 2014; Hellström, Nolan & Lundh, 2005; Hellström et al., 2007). In couplehood, the "couple maintain their treasured elements of former relationship and create a shared basis for a new relationship" (Hellström et al., 2007, p.291). My findings were consistent with studies that described how the couple interacted to sort out how they live with the difficulties in daily life (La Fontaine & Oyode, 2014; Hellström, Nolan & Lundh, 2005). The social selves of the spouse and the PLWD adjusted their perceptions of what was needed within interaction. Interaction was identified as the venue by which couple's create their relationship and their experiences in the context of dementia (Graham & Bassett, 2006; Johnston & Terp, 2015; Molyneaux et al., 2012).

### **Relationship and Accomplishing Life**

My findings focused on how efforts toward mutuality provided the basis by which the couple accomplished their life together. This concurred with other studies that used the relational approach and described how the intimate couple oriented themselves to each other in their everyday activities to accomplish life together (Hellström et al. 2007; Merrick et al. 2016; Perry, 2002; Purves, 2011). Pertinent to my study are interaction-based studies that delved more

deeply into the essence of being a couple and how different phases of interaction were associated with the couple moving through the dementia journey (Hellström et al., 2007; Keady & Nolan, 2003). Like my study, others described the difficulties and the adjustments that couples make to accomplish everyday tasks (Beard et al., 2012; Fletcher, 2018). An aspect of making it through these difficult times was the couple's ability to find significance and meaning in shared history and shared activity.

Studies that identify different phases of interactions experienced by couples and the progression of the dementia journey gave credibility to their struggles. Keady and Nolan's (2003) phases of interaction described how the couples 'work' to understand each other in the early stages of dementia. Their phases included: working alone, working together, working separately and working apart (Keady & Nolan, 2003). The description of phases that the couple was similar to my study's analytical framework because the phases of interactions were dynamic and described one partner's response or understanding of the other in the styles of interaction (enhancing, maintaining, and disrupting). In seminal work conducted by Hellström et al. (2007), they suggested that couples have "purposeful strategies to manage their life with dementia" (p.405). Hellström et al. (2007) described distinct phases of interactions that occurred over the course of dementia. The phases of interactions described by 'sustaining', 'maintaining' then 'moving on' are described to happen more or less sequentially as dementia progresses (Hellström et al., 2007). Strategies were efforts toward mutuality in that they identified specific responses that suggested how each person was taking action in their context of dementia. For example, in the maintaining phase described in Hellström et al.'s study, the PLWD was letting go of their role to make it easier on their spouse.



The description of letting go did not address explicitly how each of the spouses in the interaction came to recognize or accept letting go. The difficulty that occurred in the interaction was not addressed in the phase model described by Hellström et al. (2007). My analytical framework described the immediacy of the interaction and therefore identified that the PLWD was having difficulty letting go of previous roles. The analytical framework of my study has the potential to identify how spouses' efforts of mutuality were facilitating the letting go or making it more difficult for the PLWD.

Criticism of models developed by Keady and Nolan (2003) and Hellström et al. (2007) suggest that they did not provide a balanced perspective of the couple's life with dementia (Fletcher, 2018; McParland et al., 2018; Tolhurst et al., 2017). A recent meta-ethnography of studies exploring the conversations of families and intimate couples developed a model to explain what was happening in the interaction. Both the spouse and family member were analyzed to be expressing either dyadic-oriented goals or individual-specific goals in the interaction (Bosco et al., 2018). These different goals came about by the different appraisals related to the dementia symptoms and each person's orientation to "I-think" or "we-think". Different orientations and subsequently different appraisals influenced the intimate couples/families' experience of dementia. The approach in my study was not a dichotomous understanding of the experience of dementia but instead considered the intimate couple's process in coming to mutuality. In my study, this process involved describing the extent of shared understanding existing in the expressed response of the familiar and unfamiliar self of each spouse. Shared understanding between the spouses was identified when one of the spouses suggested their previous shared understanding or when one of the spouses restructured their understanding of their current context.

In my study, the assumption was that all responses have meaning in their expression of the person's efforts toward mutuality. Responses of both the PLWD and their spouse were an attempt to sort out how they fit into their social circumstances. People may be drawn to prioritize different aspects of their social circumstances in order to fit in. Tolhurst et al.'s (2017) study clearly described how broad social influences can impact the PLWD and their spouse differently. Tolhurst et al. described an interaction between a PLWD and their wife. In this interaction, the PLWD was interpreted to minimize the effect of not being able to keep track of things as he used to while the wife expressed her understanding towards his problems by describing her own forgetfulness. However, the interaction also includes the wife describing more responsibility she has for day to day life. She expressed sadness in the interaction because her husband did not acknowledge this difficulty. It was interpreted that the husband minimized his problems and leaves unacknowledged his wife's increased responsibility because of the stigma of dementia. The findings of Tolhurst et al. recognized the tensions produced but did not suggest how this problem could be resolved or if it will be resolved in the interaction. Application of my analytical framework to this study directed attention to the process being undertaken by the wife as her efforts toward mutuality with her husband in trying to relate to him. When the wife discussed her own forgetfulness it might be said that she was mending the interaction by equalizing the experiences of herself and her husband. This is a process in maintaining the mutuality of the relationship.

Similar tensions arising out of the stigma or a focus on the losses associated with dementia occurred in the interaction of the intimate couples in my study. This was most strikingly exemplified when Elizabeth responded to Paul by telling him he needed to look at the calendar before asking her questions about the day. Paul responded to the broader implications

of the meaning of dementia in his response of becoming upset with Elizabeth. He was interpreting the meaning of Elizabeth's response as reinforcing his losses associated with dementia and as a change in his relationship with Elizabeth associated with dementia. Elizabeth was in a process of trying to mend the relationship by reflecting on the meaning of the interaction on Paul when she stated "yes, it is demeaning". Fletcher's (2018) description of role negotiation as a type of interaction that occurs among the intimate couple could be applied to describe how Elizabeth and Paul were coming to deal with their situation so they can accomplish life together.

Fletcher (2018) described the types of interactions that occurred in the day to day lives of the intimate couple rather than as they occur over the dementia journey. Similar to my study's analytical framework, Fletcher identified what was happening in the immediacy of the interactions. For example, the type of interaction called role negotiations were similar to the mending or preserving in the maintaining style of interaction in my study. Fletcher's themes of the hardening relationship and boundary formation identify difficulties experienced in the interactions within the intimate couple. Hardening described how the relationship becomes task focused. Boundary formation identified how the spouses of PLWD sometimes coped with the increasing demands of dementia. Boundary formation by the spouse of PLWD was identified when they stated that they would stop providing physical care at some point in the anticipated trajectory of dementia (for example when the PLWD became incontinent). I would argue that these themes do not recognize or acknowledge the mutuality as an experience in the relationship but rather focus on how the spouse was experiencing difficulty in the interaction. Being able to provide a balanced view involved considering how both the PLWD and the spouse were responding to each other.

Like other studies describing the interplay between dementia and the relationship, my study identified the significance of shared history and shared activities as an element of the interaction that can foster the couple's togetherness. The doing of activities was described as a sense making activity that created purpose and contributed to the sense of identity of the PLWD (Clarke et al., 2010). The PLWD and their spouse were described as countering the losses they faced living with dementia by bringing a sense of continuity through shared history and shared activity (Molyneaux et al., 2012; Phinney, Chaudhury, O'Connor, 2007; Phinney, 2006). These situations were expressed in my study when the intimate couple described past activities such as dancing together, family stories and their wedding day. The significance of the meaningful activity was evident when intimate couples were engaged in selecting the best photographs. In the interactions between the PLWD and spouse, the couples encouraged each other's voice and opinion. These were primarily enhancing interactions. My study also identified how familiar activities and familiar social environment connected the couple in the interaction. Another compelling aspect of the situation not captured in the language but evident in the communication was how their familiar environment and being with each other seemed to be an aspect of how the couple interacts and accomplished life together. These observations were similar to Phinney et al.'s (2007) suggestion that the PLWD and older adult embody the comfort and connection they experience in their social environment and express this in their interaction.

### **Understanding Efforts toward Mutuality**

In this section I briefly discuss how different studies described how the interaction reflects the meaning of the relationship and compare these to how the interaction reflects the meaning of relationship in my study. First discussed, is the meaning suggested in applying the word mutuality to describe the relationship. Second discussed, is how certain textual elements

and ways of telling stories in joint interviews describe the relationship. Third discussed, is how the interaction occurring in the joint interview reflects the broader social implications of dementia.

Efforts toward mutuality were applied to this study to understand the relationship. Mutuality in the relationship was used in some studies as a descriptor indicating an important aspect of the relational. Balfour (2014) described that the couples' ability to maintain "a sense of mutuality in the relationship" (Balfour, 2014, p. 306) was a significant aspect of their ongoing relationship. A literature review of studies applying mutuality to describe the relationship found that the term mutuality could have different definitions leading to different understanding of relationship (Park & Schumacher, 2014). In studies describing the relationship of the intimate couple, discussion of mutuality was associated with the commitment of persons to go back and forth in order to figure out how to achieve the task or how to come to a shared understanding in relationship. For example, the intimate couple's life together was described as mutually interdependent or it was described that the intimate couple have a mutual awareness about their experience of dementia (Hellström, Lundh, & Nolan et al., 2005; Hellström, Nolan & Lundh, & 2007). The extent of mutuality has been applied to describe the relationship of the intimate couple. For example, Beard et al. (2012) stated that the intimate couples work with a "compromised mutuality that vacillates over time" (p. 8). Understanding efforts toward mutuality was meant to capture this vacillating dynamics in the interaction to understand how the context of dementia can shape the mutuality of the intimate couples and vice versa. .

Like other studies my study's interpretation of the conversational and the narrative aspects of the interaction were interpreted to reflect what was happening in the relationship. For example, the use of word 'we' and humour expressed within the intimate couple are commonly

analyzed to reflect couple togetherness when they occur in the interaction between the intimate couple (Daly et al., 2017; Graham & Bassett, 2006). Daly et al. dichotomized the relationship of the couple based on 'we' talk alone. The use of 'we' by one or both spouses when describing events or stories in joint interactions was associated with couples' successful togetherness. In my study when one or both spouses used 'we' to refer to themselves in the story or description of events it was identified as indicating that the intimate couple was aware of each other and taking each other into account in the interaction. The amount of 'we' talk in the interaction often did suggest that the couple was experiencing a recognizable context. However, categorizing the relationship based on 'we' talk alone does not recognize how mutuality is conveyed in an assortment of communication strategies and needs to be understood within the couples' larger context of dementia which includes their past and present ways of interacting. For example, humour was described as lightening the complexity of the inevitability of difficulty in shared understanding in the context of dementia for the couple (Beard et al., 2012; Flaherty, 1990). In my study chuckling or laughing was a response of the familiar self.

Davies (2011) suggested that the narrative occurring in the joint interview described how two separate storylines converge in the joint telling of the couple's stories. The analytical framework developed in my study also identified how couples' separate storyline converge by looking at their interaction. In their disrupting style of interaction, mutuality is further apart and their stories and understanding of their stories are not shared. In the maintaining and enhancing style of interaction, the couple move towards each other in shared understanding to describe their common event.

In my study, the conversational elements and the story telling used to understand the efforts toward mutuality of the couple included an interpretation of 'what was happening' in the

immediacy of the interaction as each spouse responded to the other. Studying PLWD and their family meant that there needed to be recognition that language or words can become incomprehensible within the interaction while still continuing to convey PLWD efforts toward mutuality (Boyle & Warren, 2017; Kontos, 2004; Purves, 2011). The analytical framework developed in my study interpreted how individual responses conveyed attention to the other in the interaction. In this way, the linguistic change of the PLWD that may be occurring in the interaction was captured. If the PLWD response of the unfamiliar self was not being accommodated for in the interaction then the spouse also had a response of the unfamiliar self. For example, Emmanuel went off topic in an excerpt in which Karen described a trip they made together to visit family. He was off topic, perhaps because he could not follow Karen's story. Karen carried on with the story despite Emmanuel's lack of attention. The application of the framework directed attention to understanding how the context was not recognizable to Emmanuel. Their lack of shared understanding in the interaction did not focus on his deficit or his wife's lack of responsiveness to him. This interpretation directed attention to a broad number of factors that are occurring in the responses and the interaction. In doing so, the context in which the language was interpreted became an aspect of interpreting a broader understanding of the couple's efforts toward mutuality.

Researchers have identified a need for a broad understanding of what mutuality looks like before interpreting its meaning in interaction (Forbat, 2003). Recent studies further clarify that the interaction can reflect broader social implications of dementia. For example, Tolhurst et al. (2017) applied a broadened theory of personhood to describe the narrative of the interaction of the intimate couple in a joint interview. In doing so, the joint interview of the couple was interpreted as two separate socially constructed narratives. Nilsson (2017) applied

conversational analysis with a we-ness model to describe the psycho-social implications of dementia on intimate couples. Nilsson's findings described that lack of we-ness in the interaction when the spouse was insensitive to the embarrassment obviously experienced by the PLWD when being pushed to remember something they clearly can no longer remember. Shakespeare and Clare (2005) also applied conversational analysis and described how the interaction conveyed how the intimate couple positions each other in the interaction.

The analytical framework developed in my study directed attention to understanding the efforts towards mutuality as an aspect of a broader social context that includes how the abilities and the disabilities of the PLWD are and can be understood. It directed attention to how others close to the person can foster PLWD agency amongst the stigmatized social messages associated with dementia. The study results suggest that a relational lens sees how these social messages can be an aspect of the interaction between the PLWD and their spouse. The relational lens is also a perspective that facilitates identifying the potential processes involved in overcoming these messages and fostering ability and agency of PLWD.

Applying the analytical framework of my study led to considering aspects of the couple's context of dementia that were facilitating the accomplishments of a comfortable life together and those aspects of the dementia that might be making it difficult. My study adds to the literature because it developed the concepts of the familiar self and the unfamiliar self and explicitly addressed the shifting nature of these selves. The responses of the familiar self sought to increase shared understanding (or mutuality) between the self and other; the responses of the unfamiliar self expressed distance in shared understanding between the self and other. However, the familiar self and unfamiliar self were not intended to be static interpretations of interactions but rather to interpret the response of each person, responses that may shift from the familiar self



and unfamiliar self several times during interaction. The responses of the familiar and the unfamiliar self resulted in styles of interaction within the couple. These styles of interaction were the enhancing, maintaining, and disrupting. These styles convey how mutuality of the couple was also dynamic.

Beard et al., (2012) stated that the couple does not have complete shared understanding in all aspects of daily life but rather they adjust to create a “comfortable living conditions for each other” (Beard et al., p.9). Studies agreed that this adjustment involved the spouse preserving the existing abilities of the PLWD (Beard et al.; Keady & Nolan, 2003; Molyneaux et al., 2012). The analytical framework developed in my study contributes to this discussion. The details of the interaction discerned how couples continued to be mutual in having a common goal of accomplishing life together including identifying how agency of the PLWD and their spouse was expressed in the interaction.

### **Summary of Discussion of Findings**

My exploration of intimate couples’ efforts toward mutuality grew out of my clinical practice and was an endeavor to contribute to literature applying the relational approach. The relational approach facilitated a larger life course perspective on understanding the dementia experience for the intimate couple rather than a loss focused medicalized perspective (Seaman, 2018).

I have developed an analytical framework that could underpin an understanding of the relationship of the intimate couple. I believe that the analytical framework I have developed provides a more wholistic approach to understanding how the intimate couple is living in their context of dementia. The analytical framework does this by exploring how each person is

responding to the other within their context of dementia. It identified how each spouse was making efforts of mutuality and how the intimate couple can be supported.

The intimate couples in current society lived within the medicalized perspective of dementia (Seaman, 2018). The medicalized context focused on the losses associated with disease and identified disease and disease expression as individualized. My discussion of findings has, therefore, included a discussion of how my findings fit with other studies that discussed how medicalization had influenced the interaction of the couple. Kitwood and Bredin (1992) started discussing the influences of medicalization on the interaction of others with the PLWD and personhood was a concept specifically developed to describe the impact of interaction on the PLWD (Kitwood, 1997). More recent studies considered the various dynamics that occur as both the social self of the PLWD and their spouse live within this context of dementia.

It was difficult to extricate how medicalization of dementia influenced the social selves of the PLWD and the spouse from the interaction. The social self of PLWD responded to the stigma of dementia but also had an agency to facilitate their own identity and to reinforce their relationship with their spouse. The social self of the spouse of the PLWD can become mired in uncertainty and loss in the context of dementia. My study, like others, suggested that social self of the PLWD and their spouse can express a re-orientation to reduce the dichotomization that occurs within a carer and cared for role. The interaction identified that the social self adjusted towards increased shared understanding with the other. Like other studies, my findings described the significance of the bond within the intimate couple. The focused ethnographic method in this study facilitated accessing a wholistic perspective of the intimate couples by being in an environment in which they were surrounded by symbolic reminders of who they were and how

they were in relationship. This bond experienced by the intimate couple was the impetus for them to continue to make efforts toward mutuality that in turn reinforced and re-created their couple relationship. Accomplishing life together involved their shared history and once this changes their continued shared familiarity. My findings supported that continued familiar and shared activities fostered the mutuality of the couple. Meaningful joint activities were associated with enhanced styles of interaction for the couple in my study.

Like other studies, I explored how intimate couples understand each other and how this shaped their everyday life together (Wadham et al., 2016). My study built on important work that had been done to better understand the relationship of the intimate couple living with dementia. By better understanding, the intimate couples' interactions between new insights were gathered on how to understand the ongoing abilities of the PLWD. Future studies of this type are needed to illuminate on how an embodied expression of the mutuality occurring within the intimate couples is expressed in their ongoing attention to each other in the latter stages of dementia. Effective translation of the relational approach to clinical practice is aided by applying of concepts that can help define and describe what is happening in the relationship of the intimate couple living in the context of dementia.

### **Relational Practice Implications**

My study exploring efforts toward mutuality of intimate couples underscored the significance of their relationship in how dementia is experienced. In their interaction, intimate couples sought to maintain their sense of self and their relationship with their spouses as they accomplish their lives together.

Translating my findings into changing direct care or revising policy requires the development of principles that guide and overarch the "relational spaces between patients,

families, and care-givers in care context" (Wright, Brajtman & Macdonald, 2018, p. 2). These principles are grounded in relational ethics including how health care providers perceive and understand the vulnerability of the couple in the context of our larger social context including health care systems. I identify the following principles:

1. ***The medicalization and stigmatization associated with the diagnosis of dementia is a powerful influence on the context of dementia for the intimate couple and the health care provider.*** In my initial interview with the intimate couple, I asked about how the couple's life had changed or not changed in the last few years rather than asking them to tell me how it had changed in relation to dementia. The responses that followed suggested that at times the medicalization and stigmatization of dementia were manifested in the couple's interactions and was a significant aspect of how they were experiencing dementia. Medicalization of dementia focuses on how there is no cure to a disease which causes a devastating loss in memories, abilities, and relationships. Dementia is presented as a slow and hopeless downturn of previous life as it has been known (Chaufan et al, 2012). In my study, Harold considered assisted dying as a means to relieve his wife's caregiver burden. While Mary, a spouse maintained a demanding vigilance for possible deterioration in her husband's cognition. Stigmatization means that diagnosis of dementia itself is repellant (McParland et al., 2017). Mary and Tom, Martin and Josephine, Peter and Ruth all avoided applying the word dementia or they used euphemisms (a "hiccup") to distance themselves from the diagnosis.

The medicalization and stigmatization of dementia also affect health care providers' perspectives. It is important for health care providers to reflect on how

their medicalized approach may inadvertently impact the relationship of the couple. My study suggested that medicalization and stigmatization can be overcome in relationship. Karen often adapted her responses to Emmanuel to promote his ability and facilitate his involvement in the interaction. Josephine engaged with Martin about a shared activity. In their interaction, their ongoing mutuality, suggested the strength and abilities can be supported. My study also illuminates how couples can have a more life course perspective on their experience of dementia. This was exemplified in the interactions of Peter and Ruth. The findings supported the importance of health care providers knowing how the couple is interpreting dementia and how this is impacting their relationship. Relational practice involves supporting the relationship, reducing the negative aspects of medicalization and stigmatization and fostering the couple's ongoing accomplishment of life together.

2. ***The couple living with dementia still maintains individual “agency” within their interactions with each other and with others.*** As discussed by Boyle (2014), “agency is the way the subjective self becomes the social self” (p. 1131). My findings acknowledged the agency of the spouse but furthermore, my findings emphasized the agency of the PLWD. The agency of the spouse was expressed when they supported the social self of the PLWD and when they reframed the meaning of everyday activity to include their relationship with their spouse who was living with dementia. PLWD expression of their agency often resulted in the spouse re-considering and adjusting everyday activities to accommodate for the PLWD. This was exemplified in an interaction between Peter and Ruth talking about Peter’s barbecuing. Ruth indicated

that Peter no longer barbecued but she altered her position when Peter asked why. Ruth responded saying that maybe they should try barbecuing again.

In my study, PLWD recalled past abilities, described and expressed current abilities and acknowledged the significance of their relationship with their spouse in everyday activity and life. This is exemplified when Evelyn poignantly asserted that she did not always have memory problems in response to her spouse's description of current memory problems. PLWD also projected agency though maintaining previous roles, for example, by providing hospitality during the interviews and continuing with yard work and errands. Agency was thus expressed through continued abilities (some of which may be well supported by the spouse carer) and by acknowledging previous and current abilities. For health care providers, relational care means recognizing that spouses of the PLWD respond to the agency of the PLWD. My study findings emphasized how a positive response to the agency of the PLWD by the spouse resulted in supportive interactions between them. Policy supporting the relationship involves supporting both the PLWD and their spouse as active participants in health care services.

3. ***The dualism of caregiver and care receiver does not provide a sufficient understanding or assessment of the couple's needs.*** Relational practice involves considering the significance of the unique experience of each couple in the journey with dementia. Current service provision focuses on the dualism of the PLWD with disability and the probable increased burden to the carer. This emphasis seems to be on separating the couple, which is, taking a "task-based" focus for each person that will fit all situations. The dualism results in a lack of support for the couple until they

are far along in their dementia journey until the spouses acknowledge that they are "burdened." In my study, Emmanuel and Karen were far along in their journey and were attaining well needed homecare services. Their journey to homecare was not explored fully but suggested a winding road of uncertainty in the midst of a positive past relationship, family, community, and health care provider support. The uncertainty of the journey of dementia was expressed differently by each couple. Understanding their efforts towards mutuality suggested the need to pay attention to the unique qualities of each couple's situation that could lead to supporting the couple earlier in the journey of dementia.

While dualism might lead the health care provider to a checklist of possible interventions, assessing each couple's unique experience can expand an understanding of what might help the intimate couple. It leads to exploring what is working for the couple in their everyday life and what they are trying to accomplish in their continued life together. It takes into account the couple's efforts toward mutuality, shared understanding and everyday connections. Emphasizing the couple's unique situation could possibly reduce the disability of the PLWD and the isolating experience of carer burden for their spouse. Appropriate and effective services and programs need to be implemented based on acquiring information that is sensitive to the varied needs of intimate couples and their place in the dementia journey.

4. *The interactions of the couple are dynamic and changing as each person seeks to link themselves to each other as a couple.* Health care providers working with couples should be exploring several dimensions of relationship including how couples are interacting with each other currently; aspects of past history both difficult and

positive that shape their current interaction; and their understanding of dementia and its implications on their life. The analytical framework of my study was directed toward identifying 'what is happening in the interaction' and in doing so, I developed the concepts of familiar and unfamiliar self and the styles of interaction (disrupting, maintaining and enhancing). The framework offered an understanding of the responses to the context of dementia that is embedded in a dynamic relationship. The 'responses of the unfamiliar self and familiar self' connoted a nonjudgmental (and non-medicalized) understanding of the experience of dementia. Health care providers could use these concepts to understand how the intimate couple experiences both familiarity and unfamiliarity of self in their interactions and how this can be understood as expressed in disrupting, maintaining and enhancing interactions. Health care providers could use these concepts to describe the responses of the intimate couple and subsequently develop language that recognizes and supports the efforts that the couple is making in learning to live in their circumstances.

It is suggested that the analytical framework developed in this study could be helpful to explain the communication process of the intimate couple. The intimate couple could develop their own understanding of their unfamiliar selves to reduce disrupting interactions or increase enhancing interactions.

In summary, in relational practice, health care providers develop a 'way of knowing the intimate couple' in a deep and meaningful way (Bergum & Dossetor, 2005; Wright, Brajtman, Macdonald, 2018). It takes into account how the agency of the PLWD and their spouse is responding to the medicalized social context that can diminish their experience of living with dementia. It is in the 'way of knowing' the intimate couple that the health care provider can



facilitate the agency of the intimate couples to accomplish their lives together on the dementia journey. Relational practice implications include considering the significance unique experience of the couple in their journey with dementia. Current service provision focuses on the dualism of the PLWD with disability and the probable increased burden to the carer. The analytical framework in my study offered an understanding of the responses to the context of dementia that is non-medicalized. The terms ‘responses of the unfamiliar self and familiar self’ connote a nonjudgmental understanding of the experience of dementia. Health care providers could use these concepts to describe the responses of the intimate couple and subsequently to develop language that recognizes and supports the efforts that the couples are making in learning to live in their circumstances.

### **Future Research/Knowledge Translation**

My exploration of the intimate couple’s efforts toward mutuality increased my awareness of the need for future research to understand the relationship of the intimate couple (including other informal support for the PLWD). Future research needs to explore concepts that can facilitate understanding of social selves. Examples of these concepts are the concept of agency and personhood to understand their significance in preventing excess disability of the PLWD and the burden experienced by the spouse. There are also gaps in knowledge about the reflexive processes undertaken by the PLWD and their spouse that influences their relationship. Understanding this reflexive process would facilitate having a broader understanding of how the relationship influences the context of dementia. Future research should consider how to translate the knowledge that has been developed to understand the relationship of the intimate couple to clinical practice.

Different methodological approaches to studying the interaction of the couple could provide added value to understanding how agency and personhood are expressed by PLWD. Other approaches can also more about the carers' expression of powerlessness or other challenging emotions related to dementia. I found Boyle and Warran's (2017) application of ethnographic methods effective at describing the intersubjective experience of the PLWD who experienced moderate to severe dementia. I think their ethnographic case study approach would be a valuable method to understand the agency of the PLWD in their relationship. This approach relied heavily on the researcher's intersubjective experience in the interaction. It relied on the researcher's self-reflective experiences and immediate interpretation of interaction. It may facilitate a way of acknowledging the ambiguity and richness in the interaction. I also found the analysis applying a narrative approach by Tolhurst et al. (2017) of the interaction provided a usable way to understand the interaction of the couple living with dementia. In this study, the subjective and interactional features of the joint interview were acknowledged and analyzed separately. The process acknowledges the significance of the individual agency and the sense making that occurs in the interaction. These recent studies and their approaches to understanding the interaction facilitate the development of a theoretical foundation for understanding agency and personhood for the couple living with dementia.

My study also suggested where knowledge and understanding of the couple relationship could be strengthened. Both the PLWD and their spouse interpreted what was happening in the interaction and adjusted their behavior according to a new understanding of the other. The changing perceptions of reciprocity of the PLWD and their spouse relationship could be explored further to understand how changes in these perceptions are or are not an aspect of the

reflective process. Similarly, another area of study is discerning on how the intimate couple interprets risk in everyday activity related to changing cognitive function of the PLWD.

Potential research to gain insight into how to apply an understanding of the relationship to practice is of paramount significance to facilitate appropriate and effective service provision for the intimate couple. A study question that forms the basis for considering and accepting relational care into practice would involve a participatory-action research design that includes major stakeholders. Stakeholders would include people engaged at every level of the health care system including the PLWD their spouse and other significant supports. In developing a framework for research into relational practice, it is suggested that outcomes of healthcare approaches need to reflect a life course perspective rather than a medicalized perspective. These outcomes need to be developed and considered as a way of understanding the couple's experience of dementia. The couple's adjusting and continued efforts toward mutuality that reflect the meaning and continuity in their life may be one way to consider a couples expression of their quality of life and their well-being.

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## Appendix 1: Ethical Approvals and Amendments



Research Ethics and Compliance  
Office of the Vice-President (Research and International)

Human Ethics  
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### APPROVAL CERTIFICATE

January 15, 2016

**TO:** **Barbara Tallman** (Supervisor: Lorna Guse)  
Principal Investigator

**FROM:** **Zana Lutfiyya, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2015:114**  
**"The Exploration of Intersubjectivity of the Person with Dementia and their Intimately Involved Other"**

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/orec/ethics/human\\_ethics\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**



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**AMENDMENT APPROVAL**

February 17, 2016

**TO:** **Barbara Tallman** (Supervisor: **Lorna Guse**)  
Principal Investigator [REDACTED]

**FROM:** **Zana Lutfiyya, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2015:114**  
**“The Exploration of Intersubjectivity of the Person with Dementia and their Intimately Involved Other”**

---

This will acknowledge your Amendment Request dated February 16, 2016, requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Coordinator in advance of implementation.



UNIVERSITY  
OF MANITOBA

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### RENEWAL APPROVAL

**Date:** January 5, 2017

**New Expiry:** January 14, 2018

**TO:** **Barbara Tallman** (Advisor: **Lorna Guse**)  
Principal Investigator

**FROM:** **Zana Lutfiyya, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2015:114 (HS19229)**  
**“The Exploration of Intersubjectivity of the Person with Dementia and their Intimately Involved Other”**

**Education/Nursing Research Ethics Board (ENREB)** has reviewed and renewed the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Any modification to the research must be submitted to ENREB for approval before implementation.
2. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
3. This renewal is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
4. A Study Closure form must be submitted to ENREB when the research is complete or terminated.

**Funded Protocols:**

- **Please mail/e-mail a copy of this Renewal Approval, identifying the related UM Project Number, to the Research Grants Officer in ORS.**

**Appendix 2: Posters****UNIVERSITY  
OF MANITOBA**

**Would you consider being involved in a research study to increase awareness of what it is like to live in a relationship when one of the persons have a diagnosis of dementia (including Alzheimer's, vascular or mixed types of dementia)? A relationship is any two people who care about each other (eg. spouse, siblings, daughter, son, close friend).**

**What would this involve for the persons in the relationship?**

**Both persons in the relationship would answer questions on one occasion. This interview would take about 30- 60 minutes. The researcher will audio-record the answers to the questions.**

**The researcher would come to your home about to do the interview. The researcher will always check with you prior to coming to ensure that you both are available on the prearranged date.**

**Signing a consent.** If you decide to meet with the researcher you sign a consent before participating in the study. This consent emphasizes that you can stop being involved in the research study at any time. It indicates that there are no consequences to you if you decide to stop being involved. Information is stored and distributed in such a manner that your personal identity is protected. The consent also addresses how and when information will be destroyed. There will be an opportunity after the interview is completed to further participate in this research study, if you wish.

**This research is being conducted by a PhD student of the Applied Health Science program and the University of Manitoba (U of M). The research has been approved by the Education/Nursing Research Ethics Board. If you are interested in this study and would like to discuss how you can be involved**

**further, please contact the researcher through her private phone or by e-mail. Your inquiry does not obligate you to participate in the study.**

**Barbara Tallman R.N., MN, PhD (c), Applied Health Sciences, U of M  
e-mail: [tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)**

Please contact the researcher's advisor or the human ethics coordinator for further inquiries:

Human Ethics Coordinator (HEC) phone: 204-474-7122 Email: <a href="mailto:humanethics@umanitoba.ca">humanethics@umanitoba.ca</a>
--

**Appendix 3: Letter to Alzheimer Society of Manitoba**

Barbara Tallman  
Faculty of Graduate Studies  
Applied Health Sciences Ph.D. Program  
University of Manitoba  
202 Active Living Centre  
Winnipeg MB R3T 2N2

Alzheimer Society of Manitoba  
10 – 120 Donald Street  
Winnipeg, MB  
R3C 4G2

Dear,

Thank you for taking the time to discuss with me the Alzheimer Society's approach to addressing the needs of researchers who are looking to recruit people with dementia and their significant others. As you know, I am a PhD student at the University of Manitoba. I am a RN doing a PhD through the program of Applied Health Sciences. This research study is an aspect of the requirements of completing the PhD. I am including a copy of the ethical approval of the study, the ethics protocol (including a copy of the consent) and the flyer I have developed for potential participants. .



The study I am conducting explores the way a person with dementia and their significant other connect or work towards mutual understanding. This question has not been explored in previous studies. The study focuses on the couple (the person with dementia and their significant other). The study participants are requested to be involved in the study for about 2 months. Over this time the researcher will visit their home (or the home of the person with dementia) six times. The visits are anticipated to last 45 minutes to an hour with one visit lasting from 50 minutes to 75 minutes. During these visits the researcher will interview the couple and make observations about their interactions. If the participants agree there is one session in which the researcher takes their photograph while they engage in an activity together. These photographs are latter used to further understand the way the participants engage and understand each other. Unless a separate consent is signed the photographs are not used in the dissemination or publication of results. It is emphasized throughout the course of the research that study participants can withdraw at any time.

Answering the research question will lead to greater insights and sensitivity about the way persons with dementia and their loved ones continue to strive for connection within relationship and how this connection can be promoted and supported by health care providers.

As indicated in the flyer this study has been approved by the Education/Nursing Research Ethics Board. Questions related to ethical approval can be directed to the Human Ethics Coordinator at 204-474-7122 or [humanethics.ca@umanitoba.ca](mailto:humanethics.ca@umanitoba.ca). Please feel free to contact either Barbara Tallman or her academic advisor, Dr. Lorna Guse for any questions or concerns you might have.

Barbara Tallman R.N., MN, PhD (c), Applied Health Sciences, University of Manitoba:  
e-mail: [tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)

Thank you for your consideration.

Barbara Tallman

## Appendix 4: Script for Talking to Groups About Research

### Script for Groups

Thank you for your interest in my research study today. I am very pleased to be here.

I want people to feel free to ask questions at any time.

The research that I am conducting is part of the requirement for completion of a PhD. It has been approved by an academic committee and by Education Nursing Research Ethics Board at the University of Manitoba.

The purpose of my (Barb's study) study is to explore the way people with dementia and their relative, friend or partner connect and understand each other. .

Exploring the way people understand each other requires some time being with people in their world. I have developed a study with three aspects. The first aspect of the study involves talking to both the person with dementia and their relative, close friend or partner about how an everyday activity has changed or not changed for them. It is a 30-60 minute interview with the couple.

If you think you might want to participate, I will give you a consent form to read and sign. This consent emphasizes that you can stop being involved in the research study at any time. I will protect your identity throughout the study.

After the first aspect of the study is completed I will discuss the opportunity to be involved in the second aspect of the study. The second aspect of the study involves interviewing you as a couple and separately about a significant event that describes an interaction between the two of you. These interviews are audio-taped and would last 30-6- minutes. This time I would be visiting your home 2-3 times.

If people wish they could be further involved in the third aspect of the study. In this aspect of the study I visit you in your home for about 30-60 minutes, 3 times. On the first visit, I take photographs of you together during an activity of your choice. The photographs are printed and on the second visit you are asked as a couple to decide which 10 of the photographs you like the best. Within 3-6 weeks after the photographs are taken, I will come back to your home to ask you as a couple to talk a little more about the activity that you two were engaging in at the time of the photograph.

Every aspect of the study involves signing a separate consent form emphasizing how your identity is protected, how and when information is destroyed and your opportunity to opt out of the study at any time. The photographs are for you and you alone. If you so choose there is a separate consent form that gives specific permission to use your photographs in scholarly presentation or publication.

I will be distributing flyers with my name and other contacts including the phone number of my research advisor () and the University of Manitoba, Human Ethics coordinator (204-474-7122) to contact for other questions.

If you feel comfortable talking to me now or arranging a time when we could further talk about involvement in this study I would be happy to do so.

Are there any questions?

Thank you for the opportunity to talk about my research study.

## **Appendix 5: Script for Talking to Interested Persons**

### **Script 1 for persons contacting researcher:**

“Hello, thank you for your interest in the study I am conducting to understand how couples living the community adjust to living with dementia. The research that I am conducting is part of the requirement for completion of a PhD.”

Firstly, Do you currently have a diagnosis of dementia ? or are you in a close relationship with someone with dementia?

If no, Thank them for their time and interest and indicate that this study would not apply to them.

If yes ask:

“How did you hear about this study?”

Do you have any questions about this research at this time?

This study requires the participation of both the person with dementia and a relative, partner or close friend.

Prior to making the decision to meet with me I can offer you the phone number of my research advisor () and the University of Manitoba, Human Ethics coordinator (204-474-7122) to contact for other questions.

If you are in agreement, is there a time I could meet with the two of you to discuss the research further and sign the consent if you are in agreement?

Thank you and I look forward to meeting you both. Please feel free to contact me if you have any further questions or if you change your mind. I will phone you the day before our meeting to confirm that everything is OK for the visit.”

## Appendix 6: Consents

### Informed Consent for Interview on Everyday Activities

Assigned number \_\_\_\_\_

Research Project Title: The Exploration of Intersubjectivity of the Person Living with Dementia and their Intimately Involved Other

Researcher: Barbara Tallman, RN., MN.:

email: [tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)

Advisor: Lorna Guse, RN, PhD, Associate Professor, College of Nursing, University of Manitoba

e-mail: [lorna.guse@umanitoba.ca](mailto:lorna.guse@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is being conducted by a researcher who is a PhD student at the University of Manitoba. The study results will be an aspect of the student's dissertation necessary for the receiving a PhD. The dissertation will be housed at the University of Manitoba library. The study results will be presented at academic conferences as well as to interested groups. Further it is anticipated that the results will be published in an academic journal.

The purpose of this study is to explore how two people who are close to each other understand each other when one person has dementia. It explores how the mutual dementia experience is expressed within a couple. In order to understand the mutuality of the experience between the person with dementia and the person they are close to (significant other) fully there are several research activities in which the couple is requested to engage.

This consent acknowledges your agreement to participate in one aspect of this research study. Exploring your understanding of each other involves being interviewed by the researcher. The researcher will interview you together about how your everyday activities have or have not changed in the last few years.

The interview is audio-taped. It is expected that the researcher will visit your home six times. The expected time of this visit is 30 minutes to 60 minutes. After the visit, the researcher will summarize the activity conducted and the purpose of the activity in relation to the purpose of the research. The researcher will ask if she can contact you again to be involved in this study further. You are under no obligation to be agree to be contacted or to be involved further. The researcher will encourage you to ask questions that you may have about the activity or the research.

There are several ways in which the information collected is kept confidential. Audio devices, camera, field notes and photographs will be carried in a locked briefcase. The locked briefcase will be kept in an office in the researcher's home. The data from each interview will be moved to a locked file cabinet after each interview located at the researcher's home. Data including audio files will be transferred to the researcher's password protected computer.

Your names (identifiers) will be removed from the audio-file. The researcher assigns an identity number to you once you sign the consent. The consent will be kept separately from the information collected by audio-recording and from any notes made by the researcher. The researcher will direct the transcriber (person who types out the interview) to apply this assigned number when your name is referred to in the audio-recording. Therefore, all names and identifying features of the audio-recording will be removed from the transcript (text written from the audio-recording). Audio-recording will be transcribed word for word by the transcriber. Only the researcher and the transcriber will have access to the audio-recordings. The transcriber has signed an oath of confidentiality. Audio-recordings will be deleted one month after the completion of your participation in the study. All other information except the consent signed for using your photograph if you signed this will be destroyed in five years ( December, 2021) after the researcher has completed her PhD. The information will be destroyed by deleting the files from the computer and shredding any texts (including transcripts from audio-files and notes made by the researcher).

Transcripts without the identifiers will be read by the researcher, by her academic advisor, Dr. Lorna Guse, and by member's of the researcher's committee for purposes of analysis. The transcripts will be protected by sharing through a password protected file. The members of this committee are: Dr. Laura Funk, Dr. Donna Martin and Dr. Kerstin Roger. These members are all employed by the University of Manitoba. Direct quotes may be used to illustrate a theme in the dissertation, in other scholarly presentations and in publications but there will be no reference to your identity.

There is no direct benefit for participating in this research study. There are no major risks to participating in the study. It may be uncomfortable for you to talk about the changes that have occurred because of the dementia process. If it becomes too uncomfortable for you, the researcher will direct you to resources that are available to learn more about your situation and help you feel more comfortable. The researcher will discontinue the research if you wish.

Your decision to participate in this research requires this initial written consent and your ongoing consent. You are free to withdraw at any time with no consequences to yourselves. The researcher will request verbal consent when she phones to confirm the meeting time for research activity and when arriving at each visit. You can also withdraw by telling the researcher in person, phoning and leaving a message on the researcher's voice mail (204-330-5070) or e-mail ([tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)). If you decide to withdraw, your data will be destroyed unless you agree that it may be retained by the researcher. This choice is provided at the end of the consent. A brief summary of findings will be provided to you, if you wish by December, 2016.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without

prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

**Please provide your signature:**

Participant’s Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Person able to give consent for participant (if applicable, Power of Attorney) \_\_\_\_\_ Date: \_\_\_\_\_

Researcher’s signature \_\_\_\_\_ Date: \_\_\_\_\_

**Providing summary of results:**

A brief summary of results will be available if you are interested by December, 2016. Please provide a method to send you this summary.

e-mail \_\_\_\_\_

Address \_\_\_\_\_

**Consent for further contact:**

I agree to participate in another aspect of this study that will involve further interviews

I agree that you can contact me latter to ask if I will be involved further with this study

I will decide later or call you if I am interested in being involved further with this study

**Photograph consent:**

Yes, I will allow the researcher to use my photographs for research purposes (scholarly presentations, and scholarly publications)

No, I want all the photographs to be returned to me



### **Informed Consent for Individual Interview**

**Assigned number** \_\_\_\_\_

Research Project Title: The Exploration of Intersubjectivity of the Person Living with Dementia and their Intimately Involved Other

Researcher: Barbara Tallman, RN., MN.:  
email: [tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)

Advisor: Lorna Guse, RN, PhD, Associate Professor, College of Nursing, University of Manitoba  
e-mail: [lorna.guse@umanitoba.ca](mailto:lorna.guse@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is being conducted by a researcher who is a PhD student at the University of Manitoba. The study results will be an aspect of the student's dissertation necessary for the receiving a PhD. The dissertation will be housed at the University of Manitoba library. The study results will be presented at academic conferences as well as to interested groups. Further it is anticipated that the results will be published in an academic journal.

The purpose of this study is to explore how two people who are close to each other understand each other when one person has dementia. It explores how the mutual dementia experience is expressed within a couple.

This consent acknowledges your agreement to participate in one aspect of this research study. Exploring your understanding of each other involves being interviewed by the researcher. You will also be interviewed as a couple and separately about a significant event that describes an interaction between the two of you. Information shared separately will not be shared in the interview in which both of you are interviewed.

The interview is audio-taped. It is expected that the researcher will visit your home two to three times to collect your story. The expected time of each visit is 30 minutes to 60 minutes. After the visit, the researcher will summarize the activity conducted and the purpose of the activity in relation to the purpose of the research. The researcher will ask if she can contact you again to be involved in this study further. You are under no obligation to be agree to be contacted or to be involved further. The researcher will encourage you to ask questions that you may have about the activity or the research.

There are several ways in which the information collected is kept confidential. Audio devices, camera, field notes and photographs will be carried in a locked briefcase. The locked briefcase

will be kept in an office in the researcher's home. The data from each interview will be moved to a locked file cabinet after each interview located at the researcher's home. Data including audio files will be transferred to the researcher's password protected computer.

Your names (identifiers) will be removed from the audio-file. The researcher assigns an identity number to you once you sign the consent. The consent will be kept separately from the information collected by audio-recording and from any notes made by the researcher. The researcher will direct the transcriber (person who types out the interview) to apply this assigned number when your name is referred to in the audio-recording. Therefore, all names and identifying features of the audio-recording will be removed from the transcript (text written from the audio-recording). Audio-recording will be transcribed word for word by the transcriber. Only the researcher and the transcriber will have access to the audio-recordings. The transcriber has signed an oath of confidentiality. Audio-recordings will be deleted one month after the completion of your participation in the study. All other information except the consent signed for using your photograph if you signed this will be destroyed in five years ( December, 2021) after the researcher has completed her PhD. The information will be destroyed by deleting the files from the computer and shredding any texts (including transcripts from audio-files and notes made by the researcher).

Transcripts without the identifiers will be read by the researcher, by her academic advisor, Dr. Lorna Guse, and by members of the researcher's committee for purposes of analysis. The transcripts will be protected by sharing through a password protected file. The members of this committee are: Dr. Laura Funk, Dr. Donna Martin and Dr. Kerstin Roger. These members are all employed by the University of Manitoba. Direct quotes may be used to illustrate a theme in the dissertation, in other scholarly presentations and in publications but there will be no reference to your identity.

There is no direct benefit for participating in this research study. There are no major risks to participating in the study. It may be uncomfortable for you to talk about the changes that have occurred because of the dementia process. If it becomes too uncomfortable for you, the researcher will direct you to resources that are available to learn more about your situation and help you feel more comfortable. The researcher will discontinue the research if you wish.

Your decision to participate in this research requires this initial written consent and your ongoing consent. You are free to withdraw at any time with no consequences to yourselves. The researcher will request verbal consent when she phones to confirm the meeting time for research activity and when arriving at each visit. You can also withdraw by telling the researcher in person, phoning and leaving a message on the researcher's voice mail (204-330-5070) or e-mail ([tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)). If you decide to withdraw, your data will be destroyed unless you agree that it may be retained by the researcher. This choice is provided at the end of the consent. A brief summary of findings will be provided to you, if you wish by December, 2016.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial

consent, so you should feel free to ask for clarification or new information throughout your participation.

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**Please provide your signature:**

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Person able to give consent for participant (if applicable, Power of Attorney) \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's signature \_\_\_\_\_ Date: \_\_\_\_\_

**Providing summary of results:**

A brief summary of results will be available if you are interested by December, 2016. Please provide a method to send you this summary.

e-mail \_\_\_\_\_

Address \_\_\_\_\_

**Consent for further contact:**

I agree to participate in another aspect of this study that will involve being photographed, selecting photographs and talking about your photo selection

I agree that you can contact me later to ask if I will be involved further with this study

I will decide later or call you if I am interested in being involved further with this study

**Informed Consent for Photographs**

Assigned number \_\_\_\_\_

Research Project Title: The Exploration of Intersubjectivity of the Person Living with Dementia and their Intimately Involved Other

Researcher: Barbara Tallman, RN., MN.:  
email: [tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)

Advisor: Lorna Guse, RN, PhD, Associate Professor, College of Nursing, University of Manitoba  
e-mail: [lorna.guse@umanitoba.ca](mailto:lorna.guse@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study is being conducted by a researcher who is a PhD student at the University of Manitoba. The study results will be an aspect of the student's dissertation necessary for the receiving a PhD. The dissertation will be housed at the University of Manitoba library. The study results will be presented at academic conferences as well as to interested groups. Further it is anticipated that the results will be published in an academic journal.

The purpose of this study is to explore how two people who are close to each other understand each other when one person has dementia. It explores how the mutual dementia experience is expressed within a couple. In order to understand the mutuality of the experience between the person with dementia and the person they are close to (significant other) fully there are several research activities in which the couple is requested to engage.

Exploring your understanding of each other involves allowing the researcher to participate in activities with you and photograph you. During the times the researcher is participating with you, the researcher observes the interactions that occur between the two of you. The researcher will be with you while you interact together in a normal everyday activity.

1. The researcher will engage with you in an activity of your choice for approximately 30 minutes.
2. The researcher will, with your permission photograph you and objects in your home that represent the activity and the relationship you have with each other. This photographing will take 15 -30 minutes.
3. The researcher will print the photographs taken of you and objects in your home and the researcher will ask you to select 10 photographs that both of you like the best.
4. The researcher will develop a photoalbum of your selected photographs and ask both of about these photographs several weeks after your selection.

The total number of visits for this part of the research is three. Each visit will last 30 minutes to one hour. After each visit and prior to the next visit, the researcher will summarize the activity conducted and the purpose of the activity in relation to the purpose of the research. The researcher will leave a note (card) with you with the summary of the research conducted, the date

that has been arranged for the next visit and the expected research activities for the next visit. The researcher will encourage you to ask questions that you may have about the activity or the research.

There are several ways in which the information collected is kept confidential. Audio devices, camera, field notes and photographs will be carried in a locked briefcase. The locked briefcase will be kept in an office in the researcher's home. The data from each interview will be moved to a locked file cabinet after each interview located at the researcher's home. Data including audio and photographs will be transferred to the researcher's password protected computer. The memory card that has the pictures will be reformatted after the pictures from your visit are downloaded. This will delete the pictures from the memory card. Photographs will be printed by the researcher and only seen by you and the researcher.

Your names (identifiers) will be removed from the audio-file. The researcher assigns an identity number to you once you sign the consent. The consent will be kept separately from the information collected by audio-recording and from any notes made by the researcher. The researcher will direct the transcriber (person who types out the interview) to apply this assigned number when your name is referred to in the audio-recording. Therefore, all names and identifying features of the audio-recording will be removed from the transcript (text written from the audio-recording). Audio-recording will be transcribed word for word by the transcriber. Only the researcher and the transcriber will have access to the audio-recordings. The transcriber has signed an oath of confidentiality. Audio-recordings will be deleted one month after the completion of your participation in the study. All other information except the consent signed for using your photograph if you signed this will be destroyed in five years ( December, 2021) after the researcher has completed her PhD. The information will be destroyed by deleting the files from the computer and shredding any texts (including transcripts from audio-files and notes made by the researcher).

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Photographs will not be used for research dissemination unless you sign a separate consent to do so. You have an option at the end of this form to agree to release your photographs for public viewing (in scholarly presentations and publications). You may decide not to agree to this release or to agree to this release at a later date on a separate release form (at the researcher's final visit).

There is no direct benefit for participating in this research study. You will be given the 10 photographs organized as a photoalbum that you selected in the research process.

There are no major risks to participating in the study. It may be uncomfortable for you to talk about the changes that have occurred because of the dementia process. If it becomes too uncomfortable for you, the researcher will direct you to resources that are available to learn more

about your situation and help you feel more comfortable. The researcher will discontinue the research if you wish.

Your decision to participate in this research requires this initial written consent and your ongoing consent. You are free to withdraw at any time with no consequences to yourselves. The researcher will request verbal consent when she phones to confirm the meeting time for research activity and when arriving at each visit. You can also withdraw by telling the researcher in person, phoning and leaving a message on the researcher's voice mail (204-330-5070) or e-mail ([tallmabl@myumanitoba.ca](mailto:tallmabl@myumanitoba.ca)). If you decide to withdraw, your data will be destroyed unless you agree that it may be retained by the researcher. This choice is provided at the end of the consent. A brief summary of findings will be provided to you, if you wish by December, 2016.

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This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

**Please provide your signature:**

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Person able to give consent for participant (if applicable, Power of Attorney) \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's signature \_\_\_\_\_ Date: \_\_\_\_\_

**Providing summary of results:**

A brief summary of results will be available if you are interested by December, 2016. Please provide a method to send you this summary.

e-mail \_\_\_\_\_

Address \_\_\_\_\_

**Photograph consent:**

Yes, I will allow the researcher to use my photographs for research purposes (scholarly presentations, and scholarly publications)

No, I want all the photographs to be returned to me

## Appendix 7: Field Visits

Field Visits with Couples Table					
Visits	Visit 1	Visit 2	Visit 3	Visit 4	Visit 5
Couple 1	<p>Joint interview- Engaged in everyday activity of having lunch and relational story Length of time of visit: 3 hours Audio tape: 2 hours Transcript: 49 pages Conducted in marital home</p>	<p>Individual interview with IIO One hour audiotape of interview conducted in their home Transcript: 35 pages</p>	<p>Individual interview with PLWD 20 minute interview conducted in supportive housing Transcript: 11 pages IIO present and participating intermittently</p>	None	None
Couple 2	<p>Joint interview – everyday activity and relational story Length of visit: 1 hr 15 min Lof audiotape: 50 min 35 pages</p>	<p>Individual Interviews: 20 minutes each 11 pages each</p>	<p>Engaged in everyday activity. Joint interviews: 1.5 hours 63 pages</p>	<p>Individual interview with IIO: 40 minutes 28 pages</p>	
Couple 3	<p>Joint interview Everyday activities Length of visit: 2 hours Audiotape: 1 hour 20 min. 53 pages</p>	<p>Photographing Having coffee together Audiotape: 1 hr.10 min – 30 pages</p>	<p>Photo-selection and elicitation Audiotape: 1 hr. 20 min: 44 pgs</p>	<p>Individual interview of PLWD: Audiotape: 44 min 27 pages</p>	<p>Individual interview of IIO : Audiotape : 45 min – 24 pages Photo-elicitation (joint interview) : 10 min.</p>
Couple 4	<p>Joint interview Length of visit: 1 hr. 30 min  Audiotape: 1 hr. 20 min 44 pgs</p>	<p>Photographing Having coffee Audio: 30 min-17 pages Ind.int with PLWD: 45 min.19 pages</p>	<p>Photo-selection audio 10 min- 5 pages Individual of IIO:20 min – 14 pages</p>	<p>Photo-elicitation: 20 min- 13 pages</p>	



<p>Couple 5</p>	<p>Having coffee Joint interview: Length of visit: 1 hr. 10 min 51 minutes 30 pages</p>	<p>Photographing: Having coffee 20 min. -15 pages Individual interview with Plwd: 40 min. 25 pgs Everyday activity: IIO making quilts, sat looked at photos.</p>	<p>Photo-selection 10 min.- 7 pgs Individual Interview with IIO: 40 min. – 18 pages</p>		
<p>Couple 7</p>	<p>Joint interview: Length of visit one hour 45 min. – 35 pages</p>	<p>Photographing: Having coffee 55 min: 55pgs Individual with Evelyn 15 min: 10 pgs :</p>	<p>Photo- selection/elicitation: One hour: 38 pgs Individual: One hour: 38 pges</p>	<p>Photo- elicitation: One hr. 20 min: 57 pges</p>	
<p>Couple 8</p>	<p>Joint interview Length of visit: 1 hr. 20 1 hr. 10 min. 71 pages</p>	<p>Photographing Having coffee Joint discussion 1 hr. 10 min: 41 pages</p>	<p>Photo- selection/elicitation: 40 min 27 pages</p>		
<p>Couple 9</p>	<p>Joint interview Length of visit: 1 hr. 10 mins 51 min. – 37 pgs</p>	<p>Photographing Having coffee 10 min.: 6 pages Individual interview with PLWD: 30 min. 23 pages</p>	<p>Photo- selection/elicitation 40 min. 15 min selection: 12 pages 25 min: 17 pages</p>		

**Appendix 8: Interview Guides**

**Interview Guides**

**Interview for normal everyday activity**

Grand Tour question	Probe 1	Further Probes
<p>How have your everyday activities changed in the last few years?</p> <p>(I want you to think of an activity that you both agree that you do together and describe the activity. I want you to talk about how that activity has changed and remained the same since the diagnosis of dementia)</p>	<p>Can you describe the activity that you engaged in and tell me about the activity that you engaged in? ( examples such as going for a walk, playing cards, travelling will be provided)</p>	<p>How is the activity is organized?</p> <p>Who organizes the activity?</p> <p>Who begins and ends the activity?</p> <p>What happens when one or the other is unable to engage in the way they used to engage.</p> <p>Were there days that one person wanted to do the activity and the other did not?</p>
	<p>what did this activity look like 5 years ago?</p>	
	<p>Can you describe your response to changes in the way the activity was undertaken and how they were incorporated into your life?</p>	<p>How did each person participate in the activity?</p> <p>How were changes incorporated into the activity?</p> <p>What is the importance of this activity in your life now?</p>
<p>Probe 2: Can you describe how activities that you engage in for</p>	<p>Can you describe how paying</p>	<p>how is the activity is</p>

<p>every day management has changed in the last few years. These include such things as changes in transportation, paying bills, making meals, doing groceries, mowing the lawn in summer or shoveling the walk in winter.</p>	<p>bills has changed for you?</p>	<p>organized?                  who organizes the activity? who begins and ends the activity?                  What happens when one or the other is unable to engage in the way they used to engage.</p>
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**Interview related to created everyday activity**

This interview involved photo-elicitation. The couple will be presented with the photographs of them doing an activity that was taken several weeks ago.

<b>Grand Tour Question</b>	<b>Probe</b>	<b>Further probes</b>
<p>Tell me what is happening in the photograph?</p>	<p>Tell me about how this activity has changed for you in the last few years?                  Tell me about how this activity has stayed the same for you in the last year?</p>	<p>What is there in this photograph that signifies the changes that have occurred for you?                  What is there in the photograph that signifies that some things have remained the same?                  Does this photograph provide a real picture of your experience doing this activity together?                  Can you describe what might be missing?</p>
	<p>How would you say your significant other is responding to being photographed doing this activity?</p>	
	<p>How is your significant other feeling while engaging in this activity?</p>	

	How would this photograph look 2 years ago?	
	How would this photograph look 5 years ago?	
Is there anything else in the photograph that tells you or me about your everyday life right now?	Could you apply a word or phrase to two photographs on how this photograph reflects your life now	

**Interviews of the relational life story:**

The interview guide will be administered three times. The relational life story entails asking the participant(s) to talk about their lives with separately (visit # 4, #1, appendix 2) and together (visit #5, appendix 2). Separate individual interviews are conducted followed by joint interviews.

Grand Tour question	Probes	Further Probes
Tell me about something that happened between you and the other person in the past (at least 5-10 years ago) that sticks out in your memory. “Examples provided will include a vacation experience, a wedding, a family get together, or any other event	<p>What happened between the two of you during this experience?</p> <p>How did each of you manage the situation?</p> <p>How did you think your significant other was managing or responding to the situation?</p> <p>How did you resolve a dispute if you had one?</p>	<p>What was your reaction to your significant others response to the event?</p> <p>How did each of you respond to the situation?</p> <p>Were you needing to compromise with your significant other?</p> <p>How would you respond to this situation now?</p> <p>How would you understand the significant others response to the situation?</p> <p>Can you say how this event reflects the way you get along in your relationship now?</p>

<p>Can you tell me about a situation that happened more recently (in the last 2 years).</p>	<p>What happened between the two of you during this experience?</p> <p>How did each of you manage the situation?</p> <p>How did you think your significant other was managing or responding to the situation?</p> <p>How did you resolve a dispute if you had one?</p>	<p>What was your reaction to your significant others response to the event?</p> <p>How did each of you respond to the event?</p> <p>Were you needing to compromise with your significant other?</p> <p>How would you respond to this situation now?</p> <p>How would you understand the significant others response to the situation?</p> <p>Can you say how this event reflects the way you get along in your relationship now?</p>
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**Appendix 9: Post Interview Guide**

Completed these questions after initial interview. Prior to review of transcripts.

Questions I would respond to after the first joint interview:

Who answered the door?

What was the living arrangements like?

How were people sitting?

What were the couple doing during the interview other than talking?

What was the general appearance of the couple?

What is the overall impression of the way they responded to each other?

Did it feel like one person was not including the other in the conversation? If so who and did you notice when this happened?

Did the PLWD talk as much or more than the person who did not?

Was there a sense of inclusion or exclusion from conversation at certain times in the conversation?

Was verbal or physical affection noted?

Were there tensions noted between the couple?

How did I experience the interview?

What surprised me in the interview?

### Appendix 10: Sample Analysis of the Responses of the Familiar and the Unfamiliar Self

Three examples from Chapter 4 describing the analysis of the responses of the familiar and unfamiliar self:

**\*Tom and Mary:** In this next excerpt Tom describes a hiccup in his current situation that he is having difficulty adjusting to or understanding:

**Tom:** *The biggest hiccup for me is the ability to communicate rationally without getting frustrated and Mary will say something to me and I've not fully understood what she said, so I've asked her a repetition and sometimes I'll hear a word and there's a couple of letters in the word and sometimes I'm a little slow in responding because I'm trying to analyze exactly what it is that she said and, and that creates a lot of frustration, a lot of frustration to the point sometimes I raise my voice a little more than I should and that to me that's not me and but it's hard sometimes for Mary to understand just how difficult it is for me to translate some of the things she said or fully understand where she's coming from. It's sometimes like as if I'm listening to a conversation that's half said but I've understood the first half of it. That, that is, what shall I say, to me it's probably the biggest hiccup.*

**Mary:** *The crux yeah.*

**Researcher:** *Yeah.*

**Mary:** *Yeah.*

**Tom:** *The frustration is coming up the stairs at 7:00 and putting the kettle on and poor old Mary when she gets startled she explodes.*

**Researcher:** *And you're trying, and you're trying to do your best and you can't seem to avoid that, yeah.*

**Tom:** *Yeah, I can't seem to accommodate, accommodate that, that sneaky trying to get by like a burglar coming in.*

**Researcher:** *Um-humm*

**Tom:** *Yeah. It's, what shall I say, I think the communication with Mary has been the, the moving in the house with Mary being so sensitive to hearing and no matter how hard I try to, to accommodate, it's frustrating and gets a little sometimes and that's both Mary and I am jumping all over the place.*

**Analysis of Responses Tom and Mary:**

Elements of Conversation		Internal state	External situation	Response
<b>Defining</b>				
	Example			
Tom describes self:	<i>frustrating; I can't seem to accommodate; I'm a little slow; I raise my voice; difficult ...for me to translate</i>	Difficult	Unrecognizable	Unfamiliar self of Tom
Tom describes everyday activities	<i>making tea and bringing it upstairs to Mary</i>	Difficult	Unrecognizable	Unfamiliar self of Tom
<b>Conversing</b>				
Engaged in topic together	Mary agrees with Tom's descriptions	Positive	Recognizable	Familiar self of Mary
Not engaged in topic together	Tom refers to Mary in third person	Difficult	Unrecognizable	Unfamiliar self of Tom
<b>Reviewing</b>				
Interaction about recent situation (external situation)	-how Mary used to behave and how he is behaving currently	Difficult	Unrecognizable	Unfamiliar self of Tom
Changes in recent past compared to distant past	-between what he expects to happen in interaction with Mary and what is happening. What she expects within interaction with Tom and what is happening.	Difficult	Unrecognizable	Unfamiliar self of Tom
		Difficult	Recognizable	Unfamiliar self of Mary



**Responses and continuity of self.** Tom's responses are predominantly the unfamiliar self. The interaction between Tom and Mary is the unrecognizable context of dementia for Tom. Tom's unfamiliar self is articulating difficulty with a shared understanding about the meaning of each other's behaviour within interaction. This is not how he is used to relating to Mary and Mary to him. The responses of the unfamiliar self are the process that Tom is engaging in to reconcile his continuity of self in this unrecognizable situation.

**\*\*Evelyn and John:** This interaction with Evelyn occurred close to the beginning of the first joint interview with Evelyn and John. Up to this point in the conversation John had been doing most of the talking.

**Researcher:** *What kind of changes have you noticed in your life in the last couple of years (directing question towards Evelyn)?*

**Evelyn:** *In my life?*

**Researcher:** *Yeah.*

**Evelyn:** *Well interest levels are dropping.*

**Researcher:** *Yeah.*

**Evelyn:** *No, it's not pleasant. (Evelyn starts crying)*

**Researcher:** *Yeah, you look like you're feeling really sad, feeling sad yeah. There's been a lot of changes that have been hard for you.*

**Evelyn:** *Well yeah (long pause) you feel sort of alone*

**Analysis of Responses Evelyn and John**

Elements of Conversation		Internal state	External situation	Response
<b>Defining</b>	Example			
Evelyn describes self	<p><i>...interest levels are dropping</i></p> <p><i>It's not pleasant</i></p> <p><i>You sort of feel alone</i></p>	Difficult	Unrecognizable	Unfamiliar self of Evelyn
<b>Conversing</b>				
Joint interview	No examples in this excerpt			
<b>Reviewing</b>				
Current situation	Evelyn is conveying a sense of sadness in the current context	Difficult	Unrecognizable	Unfamiliar self of Evelyn

**Responses and continuity of self.** The efforts of mutuality expressed by the responses of the unfamiliar self identify Evelyn as experiencing little shared understanding with anyone at this point. She feels alone. By articulating this unfamiliar response Evelyn informs others, she reaches out, and manifests the process of continuity of self within the interaction.

**\*\*\*Peter and Ruth:** In this excerpt Ruth talks about how she and Peter are going to move into a home built beside her daughter:

**Ruth:** *Yeah. Yeah, she said we looked after her and helped her when she needed help so she's going to help me with dad now.*

**Researcher:** *Oh is that ever nice.*

**Peter:** *Payback time I guess.*

**Ruth:** *(Chuckle)*

**Peter:** *Well I, I enjoyed the kids you know.*

**Ruth:** *Well we, we just about raised her daughter so (chuckle)*

**Researcher:** *Oh yeah.*

*Peter: Yeah, I enjoyed the kids.*

**Analysis of Responses Peter and Ruth**

Elements of Conversation		Internal state	External situation	Response
<b>Defining</b>	Example			
Peter describes self	<i>I enjoyed the kids you know</i>	Positive	Recognizable	Familiar self of Peter
Ruth describes an event/activity	<i>she's going to help me with dad now.</i>  <i>we just about raised her daughter so (chuckle)</i>	Positive	Recognizable	Familiar self of Ruth and Peter
Peter describes event	<i>Payback time I guess.</i>	Positive	Recognizable	Familiar self of Peter
<b>Conversing</b>				
Engaged in topic together	Both Peter and Ruth following topic of conversation; Peter makes novel appropriate comments; Nature of conversation is light and humourful	Positive	Recognizable	Familiar self of Peter and Ruth
<b>Reviewing</b>				
Description relates to past and current events;	Ruth and Peter helped take care of their daughter's child, now daughter is going to help with Peter	Positive	Recognizable	Familiar self of Peter and Ruth

**Responses and Continuity of self.** The responses between Peter and Ruth are the familiar self. There is a shared understanding about their circumstances. Peter's expresses his continuity of self in his connection to the family.