Commitment and the marriage relationship: The dementia experience

by

Judith C. Davies

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Commitment and the marriage relationship: The dementia experience

BY

Judith C. Davies

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Doctor of Philosophy

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Abstract

Implications of research focused on the relationship biography of the spousal dyad living at home and experiencing dementia are significant as this has been reported as a new and underdeveloped area of research. Dementia has been viewed through the lenses of many perspectives. Each lens presents a valuable contribution to the advancement of dementia care and has moved us forward toward thinking of dementia in more holistic ways. What has not been considered is the marriage relationship's impact on dementia. After all, the relationship existed prior to the dementia.

The purpose of the research study was to gain a better understanding of six couples' commitment to their marriage relationship, and how that commitment influenced the experience of dementia. Uncovering how couples interpret and enact the impact of commitment to each other and to their relationship historically and contextually became the vehicle for understanding the impact of commitment in relation to a diagnosis of Alzheimer's disease. Social constructionism was the epistemological theory of knowledge embedded in the theoretical perspective symbolic interactionism that acted to inform the narrative analysis and provided a context for the study. Based on the principles of a naturalistic interpretive inquiry I used a 'dual research strategy' by blending qualitative interviews with quantitative measures. Narrative analysis was the method I adopted to analyze narrative themes and meaning in couples' recalling of their stories about their commitment over thirty years of marriage.

Certain patterns of caring were reflected throughout the couple's marriage biographies that helped sustain them in their ability to be there for each other now that one of them had Alzheimer's disease. These patterns of caring were, namely, marriage

means (1) partnership for life, (2) reciprocity, (3) resilience, and (4) forgiveness. The couples had an enduring commitment to their relationship in spite of the diagnosis. The "us" identity of the couple changed but remained intact. Couples considered the challenge of dementia to be a "collaborative venture" – a journey into the unknown.

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Chapter One

Introduction

"*We are all reminded through art, story and dialogue that each of us is part of a very old story and a new one being written for the first time today.*" (Magill, 2004, p. 2)

An overview of the research study

Classic research and care traditions concerned with dementia (biomedical, psychological, and sociological) have mainly focused on the person with dementia and his/her spousal caregiver as individuals living in parallel relationships without the consideration of the history and context of those relationships. "Relationship seems to be missing around much of the theorizing around informal care research where relationships are centralized in the caregiving process" (Forbat, 2003, p. 68). In dementia care it is generally agreed that the goal should be to enhance the meaning and quality of life for the person with dementia as well as for their carer (Nolan, Ryan, Enderby, & Reid, 2001; Smyth, Neundorfer, Koss, Ogrocki, & Whitehouse, 2001), and yet the relationship between the person with dementia and the carer is often overlooked (Whitlatch, 2001). The marital relationship is based on a commitment between spouses and their life-long relationship to each other. Therefore, studying the marital relationship could provide insight into the strengths and limitations of the marriage commitment and the projected care needs of couples facing a dementia diagnosis. Our knowledge about the needs of couples experiencing dementia is limited. Consequently researchers, policy makers, and health service providers will need to grapple with the diversity and complexity of dementia care as our population ages and more couples face caring for each other in the midst of the dementia diagnosis.

It has been documented over the past 20 years that up to 80% of dementia care is provided in the home by family members, often spouses who occupy "centre stage" (Johnson, 1998) in an "unexpected career" (Pearlin & Anschensel, 1994). This situation creates social and interpersonal challenges to maintaining the quality of life for both the person with dementia and his or her spouse (Whitlatch, 2001). Of vital importance is the quality and history of the dyadic relationship. This historical and contextual relationship influences the quality of life of the person with dementia as well as the experience of caring (Whitlatch, 2001; Woods, 2001). Influencing how dementia is encountered and lived is the quality of the marriage relationship, and in particular commitment to the marriage, personal attributes, the couple's understanding of dementia, as well as social support. Living-in-relationship can serve to assuage suffering in the dementia journey, or it can contribute to a very difficult journey for spousal dyads and their families.

Spouses play a key role in enabling people with dementia to remain at home. I suggest the quality of their lives and capacity to care are influenced by the marital relationship as presented in the "marital biography," as well as personal biographies, physical health, personality, and structural elements such as class, age, gender, and ethnicity (Parsons, 2001). Marriage biography stems from Sternberg's (1998) narrative theory of couple and marital relations in which he suggests that people in relationships have at least three multilevel domains of narrative – mine, yours and ours (cited in Pinsof, 2002). Marriage biographies (the "ours" narrative or story) give meaning, purpose, and coherence to couples' lives together-in-relationship. It has been hypothesized that "relationships are more likely to succeed when common stories generate shared worldviews, assumptions and relationships and interpretations of events..." (Pinsof, 2002, p. 144).

Although there is extensive research addressing the impact of dementia on caregiving, there is a need to understand the impact of dementia on the marriage relationship itself. Conversely, the marriage relationship shapes the contours of the dementia landscape. Cayton (2004) challenges us to consider the role of narrative in the lives of people with dementia and to envision illness as a continuation of their stories. He envisions the diagnosis as the "once-upon-a-time of an illness, the start of the story" (p. 10). Diagnosis gives a title and meaning to a new chapter in couples' narratives. A precise diagnosis provides a new identity defined by McAdams (1995, p. 382) as "an internalized and evolving life story or personal myth" which is a sign that the marriage relationship-biography journey will be different.

Implications for research focused on the "relationship-biography" of the spousal couple living at home are significant as this is a relatively neglected area of research. "We do not know much about what goes on in the home, and how dementia care is accomplished there" (Norman, Redfern, Briggs, & Askam, 2004, p. 20). With respect to the marital relationship, commitment to the marriage may shed some light on resiliency factors that underlie quality marital relationships and act as a protective factor for the couple facing dementia. On the contrary, it has been suggested that unresolved longstanding interpersonal problems in marriage contribute to caregiver burden and aggravate dementia care (Heru, Tyan, & Iqbal, 2004), potentially putting couples at risk.

Unlike previous research, this study links or situates quality or satisfaction with respect to living-in-relationship and the commitment to the marital relationship. Marital satisfaction could be one indicator or assessment of the marriage biography or relationship. The study of dementia from the perspective of biology, psychology or sociology most often creates separate narratives and partial truths of the journey of

discovery of the reality of dementia (Cayton, 2004). Because people give meaning to their lives through the stories they tell, and the marriage biography is a central narrative in the lives of spouses, it is appropriate to study human experience with research methodology that connects with how people construct the meanings of life experience (Oliver, 1998).

Statement of the problem

It is important to look at the quality of the marriage relationship as presented through the dyad's biography at time of diagnosis of dementia because it could shed some light on the positive and negative aspects of the relationship. The relationship will undergo tremendous change and be subject to various pressures in the course of the disease process. It is the positive aspects of that relationship which are critical to supporting community care. We know that dementia increases with age, and ours is an aging society, and the "miracle cure" is many years away. Missing, in the clinical assessment of dementia, is the quality of the marriage relationship and the long-term commitment to provide care. Marriage, then, can be viewed as the fundamental platform for receiving the diagnosis of dementia. Furthermore, the marital relationship and its overall quality, will contextualize and historisize the dementia experience. The quality of the relationship and willingness to care will also be affected by the marital history. Marriages range from non-supportive relationships, which are dysfunctional, to strong supportive functional relationships. They are complex and complicated. It can be suggested that dysfunctional marriages require additional supports, less success in community living might be expected, and couples could potentially be prone to early institutionalization. Conversely, strong supportive marital relationships might require

fewer supports. Couples would demonstrate success in community living and institutionalization would be delayed.

My passion and commitment to dementia care began only days after being appointed Director of Social Work at a personal care home with 155 residents. It came as quite a shock to me to find myself an integral member of a small staff team providing continuing care and family support to a large majority of residents with moderate to severe dementia, some ambulant, some chair-bound and others bed-bound. Many of the ritualized practices of the 'institution' were humiliating and dehumanizing for the residents. I said to myself that There has to be a better way to care for people with dementia. For the next twelve years I worked towards that end. For many of those years I worked in a senior management level for the Lions Housing Centres in Winnipeg, Manitoba, a non profit organization that provides innovative housing, programs, and services for seniors. One of my jobs was to manage and develop adult day programs. I was involved in the creation of the Pacesetter Program, the first day program specifically designed for individuals with Alzheimer's dementia, which is now offered at three locations. Our management team was also involved in the design and development of supportive housing and a new personal care home with a focus on creating small home-like environments for individuals with Alzheimer's dementia. I have extensive clinical knowledge of dementia and dementia care through my personal research, specialized training and attending and presenting at several research and education conferences.

The idea for this research proposal is based on my knowledge and experience as a clinical social worker and manager of a memory assessment clinic. Over a period of two and a half years, our staff assessed 900+ patients. The majority of patients were in the early stages of dementia, most often of the Alzheimer's type. Family caregivers, most

often spouses, attended the assessment and were involved in filling out caregiver information. The quality of the marital relationship and the commitment to caring at the time of diagnosis of dementia was not taken into consideration in the assessment process. To date there is very little research on marital relationships and dementia. I believe that insight from knowledge about commitment in marriage relationships could help provide assessment strategies and intervention guidelines for situations where couples are facing dementia together.

Implications for research focused on the relationship-biography of the spousal dyad living at home are significant as this is a relatively new and underdeveloped area of research. We do know that 18 million people worldwide are living with dementia and this number is expected to double to 34 million by 2025 (Emre & Brodaty, 2005). We also know that families will be expected to provide the bulk of care to these individuals affected by dementia. In the meantime, researchers are looking beyond the medical model for a new paradigm that will help shape future care. The relationship-biography can be used with the new paradigmatic leap (Qureshi et al., 2000) of relationship-centered care.

Background to the problem

The greatest risk factor for developing dementia (of which Alzheimer's disease is the most common condition) is age itself (Corner & Bond, 2004). The prevalence of dementia increases markedly with age, doubling every 5 to 7 years after the age of 65 (Corner & Bond, 2004). Dementia is identified as deterioration in intellectual performance from a previous level and must be accompanied by a significant decline in personal and social functioning (McKeith & Fairbain, 2001). Despite scientific advances

in recent years and promising pharmaceutical treatments, most experts agree that effective treatment is still many years away.

In the meantime, it is recognized that most of the care for people with dementia is provided in the home by the family, most often the spouse who is often elderly. Researchers have linked people with dementia and their spouses through concepts of burden, stress, and person-centered care. This research has resulted in a plethora of conflicting evidence as to the most effective and efficient way to provide services and programs to support community living. Delaying institutionalization is the ultimate goal. Recent literature is calling for the need to re-conceptualize dementia care considering relationship-in-care as central. Research into dementia care to date has created four interesting 'human paradoxes.' Each paradox provides background to a specific issue. Together these issues grant legitimacy for re-conceptualizing dementia care.

Dementia care: Four human paradoxes

Paradox one: Despite the 'voluminous' literature in the field of family dementia care there is remarkably little evidence for the effectiveness of interventions.

One area of research that has dominated the field of dementia care mainly from a biomedical perspective is that of the 'burden' of caring. This research has most often resulted from the stress and coping literature (for example, Lazarus & Folkman, 1984) utilizing quantitative psychometric methods of measuring stress and analyzing coping skills of families, with the purpose of providing support to burdened families. Most of the interventions, such as support groups, education, skill-building, counseling, and respite have been associated with reduced psychological distress and improved knowledge on the part of caregivers, yet they have failed to reduce the caregiver's burden (Cummings,

2004). It has been suggested by Action and Kang (2004), that burden may be too global an outcome to be affected consistently by intervention. The reason suggested is that caregivers remain responsible for the care, and intervention is unlikely to change the responsibility of caring ("subjective burden"). Another reason adding to confusion around "burden" may be that it is measured inconsistently. In a review of ten measures of burden used with caregivers of individuals with dementia (Vitaliano, Young, & Russo, 1991), few reported content validity, convergent/divergent validity, criterion validity, or sensitivity to change.

Brodaty, Green, and Koschera (2003) reported on thirty studies involving caregivers who were predominantly spouses of persons with dementia, also finding that burden did not improve. However, their findings suggested that caregivers were often satisfied or very satisfied with their interventions, reported that his/her relationship with the patient had improved and identified helpful training elements. Also, support groups alone, single interventions, and brief interventions of courses that were not supplemented with long term contact did not work.

Paradox two: Despite research claims of burden, stress, and difficulty coping with dementia families still prefer to provide care at home for as long as possible.

Despite the difficulties of providing dementia care at home, it is what most caregivers prefer. It has been well documented in the literature that there has been too great a focus on the negative aspects of caregiving. This fits with the concept of burden. A reframe on the more positive aspects of caregiving has produced valuable insights into why caregivers 'want to care' at home for as long as possible. These insights are arrived at with a focus on positive outcomes such as caregiving gratification and satisfaction or

meaning making through caregiving, and gain in the caregiver experience (Hunt, 2003; Keady, 1999; Tarow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004) and family resilience (Boss, 2002; Patterson, 2002).

We now recognize the potential for 'gain' in the caregiving experience. This has challenged our thinking about just who are the care experts. Professions had held that position in the past. Now caregivers are in most cases regarded as "experts in their situation" (Nolan et al., 1996). Caregivers appear well-entrenched in their responsibilities prior to the recognition of dementia symptoms or professional diagnosis (Gaugler, Zarit, & Pearlin, 2003). Bowers (1987) (cited in Nolan and Keady, 1996) suggests that negotiation occurs in which family history and biography interact, resulting in the "development of commitment over time" (p. 35). Remaining loyal and committed to one another means meaningful and joyous times are created together through the recollection of earlier and happier memories, engaging in pleasant activities, cherishing the immediate moment together (Butcher, Holkup, & Buckwalter, 2001), and persevering with difficult times.

Paradox three: Despite the recent focus on 'person-centered care' the voice of the person with dementia is seldom heard.

The concept of 'personhood' and the accompanying theory of 'person-centered care' developed by Kitwood (1988, 1997) and Kitwood and Bredin (1992) has had a profound influence on the psychological perspective of dementia (Maciejewski, 2001). In this 'new personhood culture of dementia care,' the needs of the whole person are taken into consideration. The idea is to view the person with dementia as a person first, and then to consider what can be done to improve his or her quality of life (Bond, 2001).

"To improve the quality of life for people with dementia it is essential to accept that they have a voice, to facilitate it and hear it" (Killeen, 2001, p. 285). It is only recently that attention has been paid to 'hearing the voice' and understanding the perceptions and views of people with dementia. It has consistently been documented that given the right opportunities, people with dementia are able to express views and preferences about many things affecting their lives (Clare, 2002; Gillard, 2001), such as sharing a diagnosis of dementia (Wilkinson & Milne, 2003).

The new culture of dementia care highlights the fact that dementia care is not straightforward and easily understood. Nevertheless, the focus was is still very much on the individuals and the "malignant social psychology" that surrounds them (Cantley, 2001, p. 314).

Paradox four: Despite the current focus on quality of life for both the person with dementia and their caregiver, the "relationship," central to promoting quality of life, is missing from much of the literature.

In the dementia care literature, it is generally agreed that a 'cure' for the most prevalent forms of dementia, for example Alzheimer's disease, is probably many years away. In the meantime, it is agreed that the aim in dementia care should be to enhance the quality and meaning of life for both the person with dementia and his/her caregiver (Lightbody & Gilhardy, 1997; Nolan, Ryan, Enderby, & Reid, 2001; Smyth, Neundorfer, Koss, Geldmacher, Ogrocke, & Whitehouse, 2001) and yet, the interrelationship between the caregiver and the person with dementia is often overlooked (Whitlatch, 2001). In other words, the "relationship seems to be missing from much of theorizing around informal dementia care, although it is well recognized that relationships are central to the

caregiving process" (Forbat, 2003, p. 68), and, I would suggest, a barometer of the marital commitment.

It has been documented consistently over the past twenty years that 80% of dementia care is provided at home by family members, most often spouses. Creating a supportive environment at home during the course of dementia can be a daunting task. It is here where quality relationships based on mutual regard and respect will potentially act a buffer in providing an enriching experience (Nolan, Ryan, Enderby, & Reid, 2002). Of central importance, then, is the quality and history of the dyadic relationship between the person with dementia and the caregiver in influencing the quality of life of the person with dementia and the experience of caring (Whitlatch, 2001; Woods, 2001).

Significance of the study for social work

Social work with elders is considered one of the "hottest" areas of social work practice in the new millennium, according to McInnis-Dittrich (2002). She suggests that as the baby boomer generation moves from middle age to old age, the sheer size of the population and its birth cohort's experience of promoting rapid social change will force the social work profession to develop new and innovative ways to approach practice. As an increasing proportion of the Canadian population lives to a very old age the incidence of dementia of the Alzheimer's type is projected to increase dramatically. Social workers who work with persons diagnosed with dementia and their families in the community, in one or more of the many roles of counsellor, case manager, group worker, advocate enabler, educator, mediator or outreach worker, will be called upon for practice expertise in the field of gerontology.

Social work practice is founded on a long-standing commitment to the promotion of social justice and equality, to people's self-actualization, growth, healing, and well-being (Heinonen & Spearman, 2006). Social work practice has long recognized the importance of empowerment-oriented and strengths-based practice (Saleebey, 2002) and the potential of older adults to be active participants in decisions and actions that affect their quality of life (Chapin & Cox, 2001). Social justice provides an overall guiding principle for empowerment-oriented practice. Most proponents of this approach stress a knowledge base that includes "a historical view of oppression; an ecological view of the individual and group functioning; ethnic, class, and feminist perspectives that illuminate the political aspects of issues; and a cultural perspective that enhances understanding of values, beliefs, and an overall critical perspective" (Chapin & Cox, 2001, p. 166). Critical social theories have questioned the ideology of scientific objectivity and explored the social construction of knowledge (Finn & Jacobson, 2003). Strengths-based empowerment practice in working with elders will require that we develop a framework based on carer's view of valued outcomes such as quality of life of the cared-for person, quality of life for the carer, recognition and support in the caring role, and support provided in a way which values and respects the carer, recognizes their expertise, and allows them to have "have a say" (Qureshi, Bamford, Nicholas, Patmore, & Harris, 2000, p. 79).

Social workers are often called upon to provide assessments of couples experiencing dementia. Assessments might have a moral tone or judgment to them if the marriage biography is fraught with fractures, discord etc. For example an unsuccessful or poor quality marriage could be deemed undesirable by others. A critical piece of the assessment often missing is to investigate the quality of the marriage relationship and the

extent to which the couple are committed to each other and the relationship during difficult times. Social workers must be aware of "relationship histories" (biographies) of the spousal dyad in order to provide appropriate and timely information about support, referral programs, services, and alternatives to care in the home. A key social work role will be to help spouses develop a shared understanding of the meaning of dementia in their lives from a "just practice framework." That means social workers will need to examine key concepts during assessment of meaning, context, power, history, and possibilities, and their influence on strategies for maintaining meaningful roles and relationships in the early stages of dementia care (Smyth et al., 2002).

Purpose of the study

The purpose of the study was to improve understanding of the impact of the commitment to the marital relationship on the dementia experience. I highlighted the centrality of spouses' narratives, which address the history and context of their marriage biographies in general and the impact of commitment to the marriage relationship specifically, as it relates to early stage dementia. The focus of attention in the study was the spousal dyad, in a long-term marriage, in the early stages of dementia, and whose social context is the home. The couple will encounter changing roles and relationships as the dementia progresses. Spouses play a key role in enabling people with dementia to remain at home. The quality of the spousal dyad's life and capacity to care is shaped by personal biography, physical needs, personality, structural elements such as social class, age, gender and ethnicity (Parsons, 2001) and "marriage biography." In other words, commitment to the marital relationship is central to the experience of dementia and the

quality of the marital relationship underscores success or lack of success in accommodating changing roles in dementia care.

Although there is a plethora of research information on the impact of dementia on caregiving, there is a dearth of literature on the impact of the dementia on the marriage relationship itself and how the marriage relationship provides a platform for the provision of care. There is a clear need to address the issue of the nature of the marital biography and the impact of a couple's commitment to their relationship and each other in relation to the diagnosis of dementia. It will be important to know the biography stories of the couple, their encounter with the diagnosis, how they integrate the diagnosis in the context of marriage, and how they shape their ongoing biography.

Theoretical/conceptual support for the study

Symbolic interactionism is the theroretical perspective and philosophical stance I used in the study. Symbolic interactionism (SI) is an approach to understanding and explaining society and the human world. The central principle of SI is we can only understand what is going on in a situation if we understand what the actors themselves believe about their world (Charon, 2004). SI is a theoretical perspective that deals directly with issues such as language, communication, interrelationships, and community. Constructionism is the epistemology underpinning, embodied in SI, providing a philosophical way of understanding and explaining knowledge (how we know what we know).

According to social construction theory, truth holds many realities, and all of these realities are socially constructed. Meaning, then, is not discovered, but constructed. Truth or meaning comes into existence in and out of our engagement with the realities of

the world and each other. In this understanding of knowledge, it is clear that different people may construct meaning in different ways, even in relation to the same phenomenon. In this view, subject and object emerge as partners in the generation of meaning where relationships, not individuals, are considered the source of meaning. According to Gergen and Gergen (2004), constructionists favor an "ever-open dialogue, in which there is always room for another voice, another vision, another revision, and further expansion into the field of relationship" (p. 25).

Scope and delimitations

A convenience sample of six long-term married couples (N=6 couples, 12 participants) who live at home, with one spouse diagnosed with early stage dementia symptoms[1] of the Alzheimer's type were recruited for the study. Saturation was reached after the interview with the sixth couple (see Figure 1 Data collection methods). I used a "dual research strategy" (Cheung, 1999, p. 47) by blending qualitative interviews with quantitative measures.

Qualitative data was collected through in-depth biographical interviews with long-term married couples to understand each couple's shared past, from the time they met and married their present feelings about each other, and the future they envision after the diagnosis of dementia. Narrative analysis method (Riessman, 1993) was used to analyze marital biography stories as joint products in couples' recounting of their stories about their marriages of twenty years or more.

[1] Most people who work with patients and families think of Alzheimer's disease in three phases: mild, moderate and severe. These phases may overlap and the appearance and progression of symptoms will vary from one individual to the next (Gwyther, 1985). For example mild symptoms would include confusion and memory loss, disorientation (getting lost in familiar surroundings), problems with routine tasks, and changes in personality and judgment.

Marital biography stories are social constructions that are created and sustained through the social interaction of the spousal dyad. These stories do not represent the solitary voice of a single subject reflecting on his or her life experiences; they are joint products created as two or more social actors engage in developing a situationally and culturally meaningful account of the couple's life emphasizing the role of the interviewer and others in the "audience" play in initiating and shaping the telling of the stories (Gubrium & Sankar, 1994, p. 139). Culture arises in symbolic interaction and shapes the way stories are told. Shibutani (1955) describes culture as the *shared perspective* of a society or a reference group (cited in Charon 2004, p. 164) through which individuals in interaction define reality (Charon, 2004).

Each couple's relationship was assessed quantitatively around five major dimensions: (1) household tasks, (2) tension, (3) companionship, (4) affection and sexuality, and (5) commitment. The measures were used for triangulation to better understand couples' perception of their marriage relationship. The marital relationship dimensions are based on Spanier and Thompson's (1976) Dyadic Marital Adjustment Rating Scale. In addition, the Role Orientation Subscale of the Marital Satisfaction Inventory (Snyder, 1989) was used to understand the gender role perception of couples. In light of the emphasis on a couple's shared past and importance of commitment in marriage, two additional questions were asked. These two questions, refer to commitment to the spouse, and are based on the work by Swenson and Trahaug (1985), who found significantly fewer marital problems in long-term marriages when the partners' commitment is based on valuing the spouse as a unique person versus valuing marriage as an institution (Wright, 1993). Two questions were posed to each spouse: (a) Why did

you marry your spouse? (b) Why did you stay married to your spouse? Validity and reliability of these measures will be discussed in Chapter Three, Methodology.

Married couples were recruited from a memory assessment clinic (see Part Three, Methodology, for more detail). There were two interviews conducted in each couple's home (see Figure 1: Data collection methods). The first interview helped to establish the researcher's credibility and the couple-researcher 'relationship'. Because I wanted full, honest, and thoughtful answers to potentially difficult questions about the marriage relationship, establishing rapport and trust were essential. I spent time chatting about general matters, and then explaining why these interviews were important, and how the interviews fit into a larger study. It was important for me to be perceived as being present and trusted without seen as close to one particular person, or "taking sides" (Morse & Field, 1995, p.71). Demographics were collected and three quantitative scales administered (discussed in Part Three, Methodology). The second interviews lasted approximately one to one and a half hours and covered questions about (1) dimensions of the marriage relationship, (2) commitment to marriage (how it was implemented or enacted) retrospectively and prospectively, and (3) the experience and meaning of dementia.

N=6 couples (12 participants)

Home visit one (couple's home)

- Consent form signature (each spouse)
- Demographic information questionnaire (each spouse)
- Quantitative dimensions of couple's relationship (three questionnaires each spouse)
    - DAS (The Dyadic Adjustment Rating Scale by Spanier and Thompson, 1976)
    - ROR (Role Orientation Subscale by Snyder, 1989)
    - Commitment to the Spouse (by Swenson and Trahaug, 1985)

Home visit two (couple's home)

Recorded interview using semi-structured interview guide (couple together)

Figure 1: Data collection methods

Research design

I adopted a mixed-methods research design with a core methodology of narrative analysis and the use of quantitative measures. The use of these quantitative measures on the small sample size was to help gain an understanding of the spouses perception of marriage individually (discussed in Part Three, Methodology) and compare that to the joint narrative interview. That is to say, to understand how the quantitative perceptions of commitment to the marriage relationship and the dementia experience are embedded in the qualitative findings for the study.

In the social sciences, mixed methods research has become increasingly popular and may be considered a legitimate, stand-alone research design (Hanson, Creswell, Plano, Petska, Petska, & Creswell, 2005). It may be defined as "the collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research" (Hanson et al., 2005, p. 224). Mixed-methods can illuminate phenomena related to vulnerable families (such as those experiencing dementia) that cannot be captured using a singular approach (Shepard, Orsi, Mahon, & Carroll, 2002).

Design consideration in mixed-methods studies usually include determining the sequence and dominance of the paradigms to be used in the research. Sequencing refers to ordering of the data collection, whether the qualitative and quantitative data will be collected simultaneously or whether one method will precede the other (Shepard et al., 2002). Because this study is largely inductive, I chose qualitative methods as the predominant method for this study generally and narrative specifically. Qualitative

approaches to research are based on a "world view" which is holistic and has the following beliefs:

1. There is not a single reality.

2. Reality based upon perceptions that are different for each person and change over time.

3. What we know has meaning only within a given situation or context.

The reasoning process used in qualitative research involves perceptually putting pieces together to make wholes. From this process meaning is produced. However, because perception varies with the individual, many different meanings are possible (Burns & Grove, 1993).

In order to be rigorous in conducting qualitative research the researcher must ascent to an open context and be willing to let go of sedimented (long held belief) views. This process is known to qualitative researchers as **deconstructing.** The researcher examines many dimensions of the area being studied and reconstructs while continuing to recognize that the present reconstructing is only one of many possible ways of organizing data (http://www.fortunecity.com/greenfield/grizzly/432/rra3.htm).

The goal of my inductive qualitative study was to focus on the couple's experience of Alzheimer's disease (AD), while studying both spouses together. The intent of the study was to gain a rich story with a focus on commitment to their relationship. A narrative analysis was chosen as the best strategy for analyzing the qualitative data. The general view of narrative analysis was that in order to study the personal experience, a researcher needed to first learn the participants' story (Daniels, Lamson, & Hodgson, 2007). A move toward narrative inquiry is considered a move away from a position of objectivity defined from the positivistic, realist perspective toward a

research perspective focused on interpretation and the understanding of meaning (Pinnegar & Daynes, 2007). This move recognizes the researcher and the researched as study partners with each other and that both parties will learn and change in the encounter (p. 9).

Narrative inquiry fits with Postmodern research methods and is now more widely accepted as personal storytelling is now seen as a valid means of knowledge production (Fraser, 2004). Postmodern thinking is both a theory and a descriptive framework (Fook, 2005). Rosenberg (2005) suggests postmodernism questions some of the fundamental assumptions of the Enlightenment tradition in the West. These include the belief in rational human progress, universal standards, and singular truths (p. 37). Postmodern thinking acknowledges the existence of diverse and multiple frameworks of discourse and recognizes individuals as experts in their experience. "With the capacity to recognize people's strengths and engage people in active, meaning-making dialogues, narrative approaches – notably those informed by critical ideas – may help social workers move beyond a strict problem focus to a more generally explore social phenomena" (Fraser, 2004, p. 181).

I adopted a strengths-based approach to engage couples in telling their stories. This approach focuses on peoples' own capacities, vitality, abilities, strong points, talents, courage and power and not on their deficits (Heinonen & Spearman, 2006). The merits of the strength perspective are in the ability to decode, explore, discover, and develop clients own strengths in their subjective narrative experience (Yip, 2005). Marital strengths are consistent factors in enduring marriages according to Robinson and Blanton (1993), with key characteristics identified as intimacy, balances with autonomy, commitment, communication, religious orientation, and congruent perceptions of the

relationship (p. 38).The effective use of a strengths perspective in working with people with Alzheimer's disease with a focus on capabilities and abilities has also recently been reported by Yip (2005).

The following elements of the research process (see Figure 2) epistemology, theoretical perspective, methodology and methods serve to justify the methodologies and methods employed in the research and as Crotty (1998) suggests, this constitutes a penetrating analysis of the process and points up the theoretical assumptions that underpin it and determine the status of its findings (p. 6).

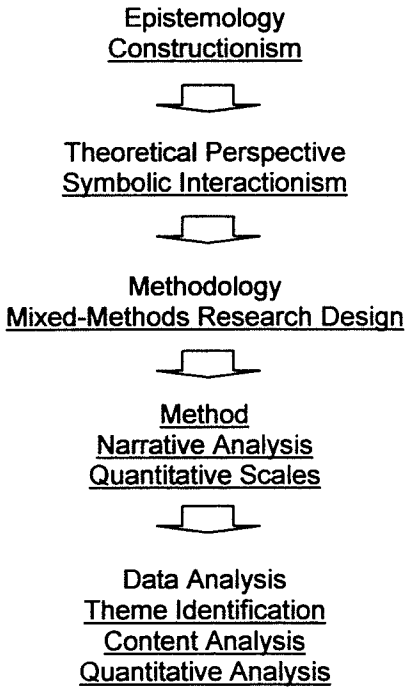

Figure 2: Elements of the research process and data analysis

Definition of dementia

Dementia – According to the American Academy of Neurology (2003), dementia is defined in the following way:

> Dementia itself is not a disease but a group of symptoms that may accompany certain diseases or conditions, marking the deterioration of a wide range of cognitive functions serious enough to interfere with normal daily life or social interactions. In addition to cognitive impairment, symptoms may include changes in personality, mood, and behaviour. Many different conditions and diseases can cause dementia. Alzheimer's disease (AD) is the most common cause of dementia. AD is a progressive neurodegenerative disease that develops gradually and is characterized by the destruction of nerve cells, especially in the area of the brain vital to memory and learning.
>
> The symptoms usually only become evident after age 65; however, they may occur as early as 40 (in rare cases even younger). The risk of AD doubles every 5 years beyond age 65. The course of the disease varies from person to person. In some the disease progresses quickly, reaching the end stage in only 5 years, while others may have it for as long as 20 years. The most common cause of death for people who survive to the end stage of AD is pneumonia (p. 6-7).

A person in the end stage of AD most often dies from the complications of pneumonia as they are no longer able to cough, eat, or move without assistance, and thus become vulnerable to chest infections. AD then becomes a secondary cause of death.

Research questions

The central question in the research study was: *How does the interpretation and enactment of commitment to the marriage relationship impact on the dementia experience?* Understanding how couples interpret and enact their commitment to each other and to their relationship historically and contextually became a vehicle for understanding the impact of their commitment. Social constructionism is the epistemology/theory of knowledge embedded in the theoretical perspective of symbolic interactionism, informing the narrative analysis and provided a context for the study. I posed the following questions regarding impact of commitment to the marriage relationship on the dementia experience.

1. How does the interpretation of the marital commitment shape the marital relationship?
2. How does the enactment of the marriage commitment affect the marital relationship?
3. What is the quality, history and nature of the marital relationship-biography?
4. How is the caring relationship experienced, lived, and responded to *before* a diagnosis of dementia and *after* a diagnosis of dementia?
5. How do couples reappraise and reconstruct meaning through changes in the marriage relationship, roles, and responsibilities after a diagnosis of dementia?
6. What are the anticipated external care requirements needed in the future?

Significance of the study

Dementia has been viewed through the lenses of many perspectives. Each lens presents a valuable contribution to the advancement of dementia care and has moved us forward toward thinking of dementia in more holistic ways, now considering the people with dementia as 'experts in their experience' and caregivers as 'experts in their experience of providing care'. As well, we have understood the impact of dementia on the individual, the spouse, and their relationship. What has not been considered is the marriage relationship's impact of dementia. After all, the relationship existed prior to the

dementia. The quality and strength of the marital relationship shapes caregivers experience of AD in a spouse. Conceptualizing dementia this way means examining how the marital relationship experience serves as an 'effect on dementia' rather than dementia simply as an 'effect on the relationship'. How the marital relationship shapes dementia has important implications for policy, practice, and research. Policy could be reframed from professionals as experts to couples collaborating on best practices for dementia care. Practice could include assessment of the quality of the relationship impacted by the marriage commitment as an integral component of care plans and interventions.

Implications of research focused on the relationship biography of the spousal dyad living at home and experiencing dementia are significant as this has been reported as a new and underdeveloped area of research.

From a sociological perspective, dementia and dementia care are very much a "social state of affairs" and are perceived differently by the person with dementia, informal caregivers, health professionals, and society (Bond, 2001, p. 50). Social science research on dementia has generally been framed by the biomedical framework and reinforced by social services that assume irreversible decline through a series of stages, characterized by normative change (Gubrium & Sankar, 1994). However, diagnosis has been a significant act in the practice of medicine, as "without diagnosis there is no meaning to our illness, and without diagnosis there can be no proper treatment" (Cayton, 2003, p. 10). As a result of this view, the person with a dementia, such as Alzheimer's disease, is seen as dominated by the disease while his or her lived experience is essentially ignored. The views of the person with dementia were seldom considered chiefly because it was believed they were not capable of expressing themselves. There is rising interest on the role of autobiographical memories, that aspect of the memory

deemed to contain emotional memories of the personal past (Mills, 1998) that are highly available for recall and comparatively resistant to being forgotten (Conway, 1990) particularly in the early stage of dementia.

It is evident that dementia care means different things in different contexts as we are not challenged with a problem simple or easy to understand (Cantly & Smith, 2001). Improved interventions do not reside in the search for strong enduring predictors of stress and burden or need, but in skillful individual assessments (Nolan, Grant, & Keating, 1996). The complexity and uniqueness of caregiving is best captured in an approach that integrates concurrent conceptual ideas with focus on relationship-centered care. Marriage relationship biography fits with the approach of relationship-centered care. The significance of considering the marital dyad as living-in-relationship with respect to dementia is (1) a marker of their strengths and weaknesses in dealing with other life challenges to ascertain capacity to care; (2) an indicator of area in the marriage biography that could form a basis for problem identification and thus a counselling guideline; and, (3) a barometer of outside support required.

From my experience working as a clinical social worker at a memory assessment clinic, I found a gap in the assessment process when one spouse was diagnosed with dementia. The quality of a couple's 'relationship' was never taken into consideration, yet, it is well documented in the literature that the willingness to provide care and support and the quality of that support is underpinned by a couple's relationship. That relationship is often bonded by a sense of duty, promise or obligation "in sickness and in health" made through a commitment in marriage. After a diagnosis was confirmed, the unaffected spouse would often ask, "Where do we go from here?" or "What can we expect down the

road?" Taking a closer look at the relationship biography will provide important insights into the caring relationship and the external care requirements (see Figure 3).

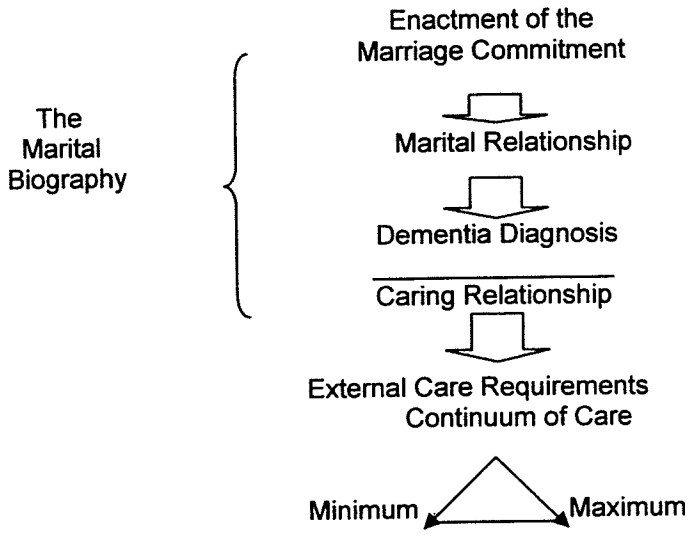

Figure 3: Impact of the marriage commitment on the dementia experience

The significance of this study was in the exploration of the meaning and understanding of the marriage commitment to the dementia experience. This is important for two reasons. First, with the proliferation of medication treatments, individuals will remain in the community longer. Families and, in particular spouses will be expected to provide care longer. Second, with average life expectancies increasing significantly, a diagnosis of dementia will become a reality for many older people. This increases the likelihood of one of the spouses developing dementia. Marriage can be a protective factor in psychological distress if the quality of the relationship is good (Cockerham, 2002). People in happy, satisfying marriages appear to have the best mental health of all and research findings suggest both spouses suffer if the marriage is unsatisfying and both spouses benefit if the marriage is good (Cockerham, 2006). Assessing a couple as living-

in-relationship and identifying the significance of their marriage commitment could be an important factor in determining the care of the spouse with dementia and the quality of life for the couple.

Chapter Two

Literature Review of Marriage and the Experience of Dementia

Introduction

Classic research and care traditions concerned with dementia (biomedical, psychological, and sociological) have mainly focused on the person with dementia and his/her spousal caregiver living in parallel. That is, couples are considered as separate individuals, rather than living-in-relationship. Researchers have connected people with dementia and their spouses to such concepts as burden, stress, and person-centered care. People living with dementia and their partners as care providers, however, are living-in-relationship. In particular, it is the historical and contextual bond found in the marital relationship that influences how dementia is encountered and lived. Relationships as described in narrative and biography allow us to understand dementia and its effects on the interaction of partners and families as a potentially important resource.

A selection of representative literature related to marriage and the experience of dementia from a biomedical, psychological, and sociological perspective has been included in this review. Each one of these perspectives "has its own language and way of telling its part of the story and interpreting it as truth" (Cayton, 2004, p. 23). The literature has been organized from a broader historical and thus logical perspective due to the complexity of the research and the amount of literature on the topic.

One area of dementia research that has been extensively studied from a biomedical perspective is the burden of caregiving. Burden has been quantified through outcome measures and psychometric testing in the stress and coping literature. However, according to Nolan et al. (1996), it is simply not meaningful to carers or cared-for

persons to reduce their care efforts to statistically significant change in a depression inventory or burden scale. A very brief overview of the medicalization of dementia and the stress and coping literature will provide a background, from a historical perspective, to a paradigm shift, and a new way of thinking about dementia care.

Dementia, stress and coping: a biomedical perspective

The medicalization of dementia

The word "dementia" is derived from the Latin *demos*, meaning "without mind", and has been in common use since the early eighteenth century (McKeith & Fairbain (2001). It became a legal status when enshrined in the Napoleonic Code: "There is no crime when the accused is in a state of dementia at the time of the alleged act" (Code Napoleon, 1808, cited in McKeith & Fairburn, 2001 p. 8). Dementia had become a medical status by the beginning of the twentieth century when clinical scientists started examining demented patients at post-mortem, and described specific changes not found in non-demented people. One significant post-mortem examination by Dr. Alois Alzheimer, and the subsequent paper he wrote on the findings, would challenge the course of medical and social understanding of dementia and consolidate the medical dominance of dementia for the remainder of the 20th century (Keady, 1999).

In 1907, Dr. Alois Alzheimer, a German physician, reported abnormal lesions (senile plaques and neurofibrillary tangles) in the brain of his 51 year old female patient Auguste D., who had died of symptoms of a 'seriously impaired memory' (Berrios, 1990, p. 358), that included progressive memory failure, language difficulties (Auguste had called a cup for milk a "pourer") and agitated aggressive behaviour (McKeith &

Fairbain, 2001). Alzheimer's disease[2] (AD) as it was to be eventually christened by Alzheimer's mentor, Emil Kraeplin, was found on the basis of that one identified case study (Keady, 1999). Although Alzheimer's disease is considered the most common cause of dementia and a degenerative disease, there are approximately 70 to 80 different types (American Psychiatric Association, 1994).[3] What the different types of dementia have in common is the loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient magnitude as to interfere with an individual's daily functioning. In everyday life this loss of intellectual function of the person with dementia is perceived by professionals and lay people as a problem because it can lead to behaviour changes and changes in personality (Bond, 2001). Although dementia is often thought of as developing on a continuum of 'stages' (early, middle, late), it is the early stage, with the emphasis on diagnosis, that has become the focus of much of the recent literature in the field. Whitehouse (2003) suggests, "let us be sure we know what and who we are labeling with early dementia and for what purpose" (p. 872).

The Guidelines for Early Detection, Diagnosis and Management of Dementia were recently updated by the American Academy of Neurology (2003). Of central concern was "where does aging stop and dementia begin" (p. 872). The American Geriatric Society Clinical Practice Committee recommended that the support to recognize dementia early should be considered in the context of the motivation of those encouraging early recognition (for example, pharmaceutical companies), the benefit of identifying truly reversible forms of dementia, and the advantages and disadvantages of

[2] Alzheimer disease is the accepted spelling used to denote the disease in Canada (without the's). To be consistent with most of the research studies I have used the more universal spelling of Alzheimer's disease.
[3] Some of these include: Vascular dementia, (e.g., Multi-infarct Dementia), Anoxic Dementia (e.g., Cardiac Arrest). Traumatic Dementia (e.g., Dementia Pugilistica [boxer's dementia], Infectious Dementia (e.g., Creutzfeld-Jacob Disease), Toxic Dementia (e.g., Alcoholic Dementia), and HIV AIDS.

labelling someone with a degenerative process like early Alzheimer disease. Further to this the committee suggested that "labeling the extreme of normal age-related cognitive impairment as a discrete terrifying disease such as AD raises questions about the value of medicalizing age-related changes. Is the terror or AD worse than the actual state?" (p. 872).

Stress and coping

From a biomedical perspective, dementia and the impact of the condition on family caregivers can best be referred to as a 'personal tragedy' and the people with dementia can best be understood as 'victims' (Bond, 2001, p. 45). From this perspective, research most often focuses on determining the type of stress and burden that carers experience and how these can be relieved (for example, Lazarus & Folkman, 1984; Pearlin, Mullen, Semple, & Skaff, 1990) through the design of support services (Nolan, Ryan, Endbury, & Reid, 2002). It is important not to underestimate the insights gained from research into stress and coping, for example, caregivers use of 'problem-focused' and 'emotional-focused' coping styles (DeLongis & O'Brien, 1990).

Current theories define coping as a process in which people use cognitive and behavioral methods to manage internal or external demands that are viewed as either taxing or exceeding the person's resources (Pearce, Clare, & Pistrang, 2002). These theories point out that the coping strategies people use will be based on their appraisal of their situation and evaluation of the resources available to them. There are two types of coping strategies, those considered to be emotion-focused and those considered to be problem-focused. Emotion-focused strategies are considered primarily cognitive and are directed at lessening emotional distress by using avoidance, minimization, distancing, selective attention, positive comparisons, and wresting positive value from negative

events (Kneebone & Martin, 2003). Problem-focused strategies are considered primarily those used for problem-solving such as defining the problem, generating alternative solutions, weighing the alternatives in terms of the costs and benefits, choosing among them, and finally acting (Kneebone & Martin, 2003). "What coping strategies may be beneficial in a given situation are considered to depend on the nature of the stressor" (p. 2). The stress and coping perspective conceptualizes a relationship between stress, coping, and adaptation. It is referred to as a 'transactional model' that views the person with the environment in a dynamic mutually reciprocal, bi-directional relationship (Kneebone & Martin, 2003).

Two large critical reviews of empirical studies that were based on Lazarus and Folkman's (1984) stress and coping model were recently reported (17 studies by Gottlieb & Wolf, 2002; 16 studies by Kneebone & Martin, 2003). Both studies reviewed coping by those caring for persons with dementia living in the community. Gottlieb and Wolf (2002) were looking for consensus regarding ways of coping that serve to protect health and whether there was enough rigor and precision to draw conclusions about any consensus. Findings reported that, by and large, the majority of the coping studies were not faithful to the transactional theory's emphasis on stressor and stage specificity, the dynamic, changing character of coping efforts that unfold over time, and the influence of the larger social context on adaptational outcomes (p. 320). Therefore the authors suggest that interpretation of the seventeen empirical findings on caregiver coping is questionable. Kneebone and Martin (2003) report similar difficulties interpreting the sixteen studies they reviewed. They were looking at coping in an attempt to establish the implications for interventions aimed at improving caregiver adjustment. The research from these studies suggests that there is a general tendency towards problem-solving and

acceptance styles of coping to be advantageous to caregivers with dementia. Despite this finding, the authors conclude that the ability to do research to inform the clinician is severely limited if "the objective is to identify what coping works, for what problem, and when" (p. 14).

A recent study by Chadiha, Rafferty, and Pickard (2003), using the stress and coping framework by Pearlin et al. (1990), examined the influence of stressors, caregiver appraisal on the marital functioning of spousal caregivers, and social support. Pearlin et al. (1990) suggested that coping and social support can potentially intervene at multiple points during the stress process (p. 583) and be used in adaptive ways to lessen the negative effect of stressors on caregiver well-being. Social support, defined by Steward (1993), is the interaction with family members, friends, peers, and health professionals that communicate information, esteem, practical aid, or emotional help. When these communications are perceived as supportive they have the potential to enhance coping, thus moderating the impact of stressors (Steward, 1993). Receiving church support was associated with increased marital functioning, as well as high levels of caregiving satisfaction. Lower levels of caregiving burden were associated with increased marital functioning.

Roberts, Browne, Gafni, Varieur, Loney and Ruijter (2000) conducted a systematic review of the literature for evidence of effective and efficient modes of care (considered social support) for persons with dementia and their caregivers living at home. Caregivers reported satisfaction with respite care, counselling, and day programs to the point that, when using these services caregivers may keep his or her relative in the home longer, although these programs actually had little effect on the behavior of clients with dementia. A similar meta-analysis of 24 published articles reporting intervention

strategies designed to help caregivers cope with the burden of caring for a family member with dementia including support group, education, psychoeducation, counselling, respite care, and multicomponent reported similar findings (Acton & Kang, 2001). Overall the analysis showed that collectively the interventions had no effect on caregiver burden. Only the category of multicomponent interventions significantly reduced caregiver burden. A more recent meta-analysis of 30 studies (Brodaty, Green, & Koschera, 2003), reviewing research in psychosocial interventions for caregivers, predominantly spouses of persons with dementia, reports significant benefits were found through reducing caregiver psychological distress, and increasing caregiver knowledge. However, caregiver burden did not improve.

The bulk of dementia family research has been conducted by means of surveys, and closed-ended interview methods that rely on standardized psychometric instruments, such as the burden scale used in the above study. Others include various depression and anxiety scales, symptom checklists, and structural diagnostic tools (Butcher, Holkut, & Buckwalter, 2001). A paper critiquing ten measures of burden (Vitaliano, Young, & Russo, 1991), that have been used with caregivers of persons with dementia, suggest that relatively few report content validity, convergent/divergent validity, criterion validity, or sensitivity to change. Acton and Kang (2001) point out that "burden may be too global an outcome to be affected consistently by intervention" (p. 349).

This section has briefly summarized developments in the biomedical perspective of dementia that impacts on dementia care. It has also highlighted the effectiveness of practice and research in dementia care. It is clear from this review that we do not want to "abandon a scientific approach" as Harrison (1992) argues, but instead "we need to integrate humanistic perspectives with it" (p. 420).

From coping to experiencing: broadening the research context

A preoccupation with the negative aspects or pathological aspects of care (Nolan, Ingram & Watson, 2002; Vitaliano, Young, & Russo, 1991), and the relative failure of research to translate into 'workable solutions' (Roberts, Browne, Gafini, Varieur, Loney, & Ruifter, 2000), have resulted in the need to reframe the "theory-practice gap" (Gottlieb & Wolf, 2002; Nolan, Ryan, Enderby, & Reid, 2002). Recent trends in research support an approach that pays more attention to the dynamic and changing nature of the experiential world of persons with dementia and from families (Clare, 2002; Clare & Pistrang, 2002; Menne, Kinney, & Morhardt, 2002; Smyth, Neudorfer, Geldmacher, Ogrocki, & Whitehouse, 2002; Whitlatch, 2001).

Gerontological social workers are often called upon to evaluate how family members are coping with caring for older persons with dementia (McInnis-Dittrich, 2002; Kramer & Vitaliano, 1994). These evaluations often include assessment of stress and psychological resources using traditional coping measures (burden scale). And yet, inconsistent findings and limited elucidation of potential relationships of coping with outcome measures have made it difficult to establish construct validity of coping measures in many studies (Gottlieb & Wolfe, 2002). This leads us to consider a reappraisal of whether our methods of attempting to 'measure' success are in fact the most appropriate (Nolan, Keady, & Aveyard, 2001). There is a growing body of literature that examines positive outcomes among caregivers, such as gratification and satisfaction, finding or making meaning through caregiving, and gain in the caregiver experience (Hunt, 2003; Keady, 1999; Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004), as well as family resilience (Patterson, 2002; Boss, 2002).

The social work profession has long recognized the importance of empowerment-oriented and strengths-based practice (Saleebey, 2002) and the potential for older adults to be active participants in decisions and actions that affect their quality of life (Chapin & Cox, 2001). An empowerment-oriented strengths-based practice approach includes the basic assumption "that elders, including those experiencing a severe physical disability, and all but extreme levels of dementia, possess the capacity to be active participants in the helping process" (p. 166). Social justice provides an overall guiding principle for empowerment-oriented practice. Most proponents of this approach stress a knowledge base that includes a historical view of oppression; an ecological view of individual and group functioning; ethnic, class, and feminist perspectives that illuminate the political aspects of issues; and a cultural perspective that enhances understanding of world view, beliefs, behaviours, and an overall critical perspective (Chapin & Cox, 2001, p. 166). Critical social theories have questioned the ideology of scientific objectivity and explored the social construction of knowledge (Finn & Jacobson, 2003). Strengths-based empowerment-oriented practice in working with elders requires that we develop a framework based on carers' views of valued outcomes, such as quality of life of cared-for persons, quality of life of the carer, recognition and support in the caring role, and support provided in a way which values and respects the carer, recognizes their expertise and allows them to "have a say" (Qureshi, Bamford, Nicholas, Patmore & Harris, 2000 p. 79).

Dementia and personhood: a psychological perspective

The concept of 'personhood' and the accompanying theory of 'person-centered care' developed by Kitwood (1988, 1997) and Kitwood and Bredin (1992) have had a profound influence on the psychological perspective of dementia (Maciejewski, 2001).

Traditional psychological approaches to dementia assessment have adhered to the biomedical model focusing on standard neurological testing of cognitive deficits, such as recall of events, word finding, aspects of attention, and confrontation naming (Sabat, 2002). Therapeutic approaches have focused on behavioural problems viewed as 'deficits', such as aggression and agitation. A focus on the new way of thinking and the new culture of dementia care is to view people with dementia as people first and then consider what could be done to improve their quality of life (Bond, 2001).

Kitwood (1988) first developed the concept of 'personhood' in reaction to failing residential care environments for people with dementia. He equated these environments to the development of a 'malignant social psychology', referred to as bad care that inhibited the full expression of people with dementia. Such malignant elements as disempowerment (helping a person do what they are still capable of doing), infantilization, implying the mentality of a child or baby, and stigmatization (verbally labelling as a diseased object or outcast), he believed, could be identified, appraised and overcome, resulting in improved care and a greater sense of well-being (Keady, 1999). Kitwood (1988) has presented us with a formulation of dementia (**D**) as having five key factors as is viewed in this equation:

$$D = P + B + H + NI + SP$$

P stands for the person's personality, and includes coping styles and defenses against anxiety; **B** biography and responses to the vicissitudes of later life; **H** health status, including acuity to the senses; **NI** the neurological impairment, separated into location types and intensity; and **SP** the social psychology that surrounds the person with dementia everday (Keady, 1999; Maciejewski, 2001). The experience of dementia then is

unique to the individual and depends on the interaction of the five components of the equation. The importance of the social psychology of the environment, including relationships in which the person interacts, is seen as an important influence. Personhood is defined by feelings, emotions, and the ability to live in relationships (Bond, 2001). Kitwood suggests "people with dementia are often highly competent in these areas, sometimes more so than their informal caregivers" (Bond, 2001, p. 47).

Kitwood (1997) suggests "when the concept of personhood retains both its ethical and its social-psychological meaning that it serves its proper function" (p. 12). Ethical considerations for the theory of personhood have to do with our moral obligation as a society to care for one another. Several of the most basic principles include: *respect for persons* based on acknowledgement that persons have a certain worth and fundamental equality; *autonomy*, based on the respect for the ability to make free and authentic choices; *beneficence*, based on performance of acts that benefit others; and *non-maleficence*, based on refraining from doing harm to others (e.g. The Hippocratic Oath for physicians to 'first do no harm') (Harrison, 1992, pp. 431-432).

Social-psychological consideration for the **theory of personhood** must meet the following criteria: (1) it must be reflexive, meaning that the categories used to explain people with dementia be applicable to the professions who use them; (2) the person must be seen as a social being; (3) it must be developed showing how people can change, for good or ill; (4) it must bring out the most relevant psychological differences between people; (5) it must be compatible with what neuroscience tells us about the brain functions in both health and illness; (6) it must shed light on the psychological predicament of people with dementia and suggest what they might need; and (7) it must tell us something about the nature and meaning of good dementia care (Kitwood, 1997,

pp. 14-15). According to Kitwood, this model brings together the framework of symbolic interactionism (the manifest aspects of social life, as discussed earlier) and depth psychology (unconscious processes).

Kitwood refers to the melding of these ideas as 'the psychology of personal being' where the nature of personhood is 'being a person' acquired through the acquisition of language that involves not just the presence of *self* but also *self-concept*: 'Me' as well as an 'I' (p. 14). According to Mead, the 'I' is simply that part of all humans that goes untouched by other humans – that part of what we do is nonsocial and not controlled, and the 'Me' becomes the socially shaped and controlled actor (Charon, 2004, p. 92). The term self-concept is described as the "totality of the individual's thoughts and feelings with reference to himself [or herself] as an object" (Charon, 2004, p. 81). Psychology has legitimately used two main patterns of development when it comes to the idea of self, the 'adapted self', which refers to the person as highly and tightly socialized, and the 'experiential self', which arises from being with others in conditions of equality, mutual attention, and mutual respect (Kitwood, 1997).

Almost always before dementia becomes noticeable, there are losses in the adaptive self such as difficulty remembering where the car was parked, managing finances, taking phone messages, etc. The experiential self remains open to growth in dementia in an environment in which the person is provided with understanding, loving support, and acceptance. In fact, the more joyous and fulfilling aspects of dementia care for both care giver and care receiver are likely to be based on the experiential self, such as validation of the subjective truth of a person's experience with an obsessional concern of 'cognitive rectification' (Kitwood, 1997, p. 18). For example, "*I just feed my children*

lunch," says an 80 year old woman. To that you would use positive reframing and reply "*I think that you are such a good mother to make such a nice lunch for your children.*"

Dementia care and personhood: a social-psychological perspective

As discussed earlier, the dementing process can be viewed as an outcome of the interaction of neurological impairment (disease), personal psychology (personhood), and social psychology (interpersonal and environment). Kitwood and Bredin's (1992) argument in formulating a *theory of dementia care* is to suggest that a "dementing illness need not necessarily involve dismantling of the person and that dementia sufferers can be in a state of at least relative well-being" (p. 270). Kitwood and Bredin (1992) identify the problem of 'bad care' and the corresponding 'ill-being', as a lack of insight of caregivers into what 'good care' looks like.

The disease model of dementia care suggests that there is a clear division between us (members of a 'normal' population) and them (the dementia sufferers). *We* are considered basically undamaged. *They* are considered damaged, derailed, and deficient. *We* may not always be effective carers, so "there is a need for training to give knowledge about *their* illness; and develop skills, especially in managing *their* challenging behaviours. So in the long run, *they* will have to learn to accommodate themselves to the provision *we* make for them" (p. 272). Kitwood and Bredin (1992) propose a different view of this problem: both *we* and *they* are human beings with failures, limitations, and suffering. A 'therapeutic awareness' drawn from psychotherapy and counselling suggests that we are, or may be, part of the problem if we allow personal distress and self-defeating patterns to interfere with helping others.

In addition to the idea of awareness of helpers, the theory proposes psychological insight into interaction patterns, resulting in individuals responding to social processes. By adulthood, it is suggested, the individual has acquired strategies for dealing with people and situations through a particular array of defense mechanisms. There is evidence to suggest that these patterns persist throughout one's lifetime. Kitwood and Bredin (1992) refer to these patterns as the '*fluid-frozen*' construct. The extreme state of personal being is described as '*shattered*' and approximates a severe psychotic breakdown, such as when a person with dementia is left isolated and unsupported. The authors suggest that in adult life many people remain more or less in the *frozen state*, maintaining their defenses and developing their resources based on the same personality structure. Their subjectivity receives little further nourishment. The *frozen state* is maintained by various forms of collusion, particularity in organizations where individuals work in restricted ways, resulting in burnout and depression of staff. The authors contend that a more desirable way of life would involve greater intersubjectivity, and a continuing opportunity for people to be fluid, to grow and change. These ideas bring the person with dementia and the 'other' into a single frame, thus opening the way for exploring the basis of good care (pp. 276-278).

When Kitwood and Bredin (1992) speak of relative well-being, they suggest a list of 12 twelve behaviors indicators that can be observed in any care situation. The indicators are as follows: (1) the assertion of desire or will; (2) the ability to experience and express a range of emotions (both positive and negative); (3) initiation of social contact; (4) affectional warmth; (5) social sensitivity; (6) self-respect; (7) acceptance of other dementia sufferers; (8) humour; (9) creativity and self-expression; (10) showing evident pleasure; (11) helpfulness; and (12) relaxation. The underlying rationale for these

indicators of well-being is the notion of 'global states' that include personal worth, agency, social confidence, and hope. Ill-being may be understood psychologically as a loss of one or more of these global states as inevitable with the advancing of dementia. Although not empirically justified, the authors claim that these indicators are deemed valid by consultation with experts in the field. The crucial point is that these indicators are dependent on cognitive skills, the most common measure for people with dementia. This makes them specific to, but not exclusive to, people with dementia. They are considered part of the shared experience and because of that we consider that the indicators have face validity (p. 282). Thus, the idea of incorporating personhood into the dementia experience has important implications for assessment, practice, and research. It has given voice to the subjective experience of people with dementia.

The subjective experience of people with dementia: a 'person-centered approach'

"It's as if my head was full of bubbles, like a glass of lemonade and sometimes the bubbles all rise to the surface and my head clears. Then it slowly fills with bubbles again." (Keady and Gillard, 1999, in Cantley, 2001, p. 79)

Many impressive developments have been made towards understanding the subjective experience of people with dementia (Pratt & Wilkinson, 2003), and that experience is often referred to as a 'person-centered approach' (Nolan et al., 2002). Keady and Nolan (1995) reported on such an approach in their developmental model of dementia outlining nine stages experienced by people with dementia. This process using a person-centered approach based on the experiences of people with dementia has challenged the staging model of dementia based on the medical model where dementia is

viewed as questionable, mild, moderate, or severe. The stages Keady and Nolan propose are as follows:

- Slipping – the person gradually becomes aware of lapses in his or her memory;
- Suspecting – the lapses become more frequent, cannot be so easily discounted and the person suspects that something is not right;
- Covering up – the person makes a conscious effort to hide his or her difficulties;
- Revealing – the person shares his or her concerns with someone close;
- Confirming – outside help is sought and a diagnosis obtained;
- Maximizing – the person adapts by using coping strategies;
- Disorganization – there is a diminishing ability and awareness;
- Decline – the demands of care become more prominent;
- Death

(In, Cantley, 2001, p. 80)

An important point from this study is that people with dementia were aware of having Alzheimer's disease, and were willing and able to talk about it, and they had valuable insights to share. Of critical importance to research and practice in dementia care was the idea that people with dementia often consciously 'cover up' or secretly hide their difficulties and often 'make up stories to fill in the gaps' (Keady & Gillard 1999).

Harris and Stern (1999) explored the concept of the definition and preservation of self in people with dementia. The authors reported feelings of loss on multiple levels for people with dementia including loss of independence, roles, competency, memory, and relationships. These losses resulted in emotional reactions, including frustration, anger, embarrassment, and humiliation. These emotional reactions resulted in a number of coping strategies, such as using daily routines, lists, humour, support from family, support groups, and faith. A typology of five different reaction patterns was developed in response to better understanding the dementia experience: (1) "I'll live till I die"; (2) "I accept what I have"; (3) "There is nothing wrong with me"; (4) I am just struggling through the day"; and (5) "I'm giving up" (Harris & Stern, 1999). More recently, Clare (2002) interviewed people with dementia and their partners, focusing on coping

mechanisms, and found a range of experiences in coping such as holding on, compensating, developing a fighting spirit, and fighting back.

Good care = good quality of life

Person-centered care has become a major force underpinning quality of care in dementia (Woods, 2001), as the capacity for positive change has been 'consistently underestimated' (Lawton & Rubenstein, 2000). Consequently, the widely accepted goals of care focus not on the maintenance (Ory, 2000), but on abilities and residual interests (Crisp, 1999; Zgola, 1999) as social inclusion is considered a precondition of personhood (Moriarity & Webb, 2000). Capturing the experience of the person with dementia must be reflected in interventions (Nolan et al., 2002).

The concept of "quality of life" plays an important role in research on the care of persons with dementia (Jennings, 1999), acting as an outcome measure (Logston & Albert, 1999). Quality of life (QoL) is an 'elusive' concept that has been defined in a number of ways depending on the context and conceptual orientation of the investigator. Logston and Albert (1999) suggest, for example, that a bioethical view of QoL would be defined as "the essential conditions beyond mere survival that are needed for individuals to have experiences that provide meaning and joy to their time" (p. 3). This example raises ethical issues regarding the normative view around the value of life that surrounds the concept of quality of life. Jennings (1999) distinguishes two values of human life: 'instrumental' and 'intrinsic'. Something, for example, human life, has instrumental value when it is valuable only for the sake of something else. Human life has intrinsic value when it is valuable for its own sake, when it is taken as a given and treated as an end in itself, and not just a means for something else. The author claims that the term 'quality of

life' seems to suggest instrumental or contingent value only; it seems to suggest that life is not intrinsically worthy of respect, but can give greater or lesser value according to circumstances. "From this perspective quality of life is part of a broader normalizing ideology in the mainstream culture" (p. 96) and works to the detriment of persons with dementia by perpetuating their stigmatization (non-personhood bias). To ensure that quality of life assessments have intrinsic value, the author believes they can only be made subjectively by persons for themselves, about themselves (Jennings, 1999).

Lawton (1997) has defined quality of life both conceptually and operationally by including both instrumental and intrinsic values as the "multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual" (p. 91). Brod, Stewart and Sands (1999) reported on the domains of QoL that could be reliably reported on by people with dementia with the introduction of their Dementia Quality of Life Instrument (D-QoL). The dementia specific domains and a definition of each are as follows:

- Aesthetics – enjoying/appreciating beauty, nature and surroundings (animals, music)
- Positive affect – experiencing humor (laughing, joking), feeling happy, cheerful, content, hopeful
- Negative affect – experiencing worry, frustration, depression, anxiety, sadness, loneliness, fear, irritability, nervousness, embarrassment, anger
- Self-esteem – feeling accomplished, confident or satisfied with self, able to make own decisions
- Feeling of belonging – feeing lovable and liked, useful

(Brod, Stewart, & Sands, 1999, p. 13)

A critique of this measure and eight other popular measures of QoL for dementia developed between 1992 and 2002, were recently reviewed by Ready and Ott (2003) in a

review of fourteen articles.[4] According to these authors, the D-QoL is unique because it is the only scale developed exclusively to be administered to patients and is deemed appropriate for patients in the mild to moderate stages of dementia. In a sample of 99 patients diagnosed with early to moderate dementia, 4% of participants could not correctly answer the screening questions. For those who completed the DQoL, internal consistency reliabilities for subscales were moderate to high (.67 to .89) and two week test-retest reliability for a subset of participants (n=18) ranged from .64 to .90. Convergent validity was indicated by correlations on the Geriatric Depression Scale and 4 D-QoL (r = .48 self-esteem, r = .61 positive affect, r = -.64 absence of negative affect, r = .42 feelings of belonging) (Ready & Ott, 2003, p.7).

Assessing quality of life in person-centered care "cannot be considered an attribute capable of being reduced to a single numeric estimate" (Jennings, 1999, p.98) although lack of insight common in dementia increases with severity and may compromise the validity and reliability of self-reports (Ready & Orr, 2033). Although person-centered care has 'transformed' our thinking and to a degree practice in dementia, Nolan et al. (1992) would argue that *it does not fully capture the interdependencies and reciprocities that underpin caring relationships.*

The experience of 'living with dementia': a sociological perspective

Charon (2004) defines sociology as the study of society, as well as all organized life, from small groups and formal organizations to communities and societies. Sociology makes the assumption that "humans have always existed within society, and that society

[4] Alzheimer Disease Related Quality of Life (ADRQL); Cornell-Brown Scale for Quality of Life (CBS); Dementia Care Mapping (DCM); **Dementia Quality of Life (D-QoL)**; Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP); Quality of Life in Late Stage Dementia (QUALID); Quality of Life Alzheimer's Disease (QOL-AD); Quality of Life Assessment Scale (QOLAS).

is the source of our qualities as a species," for example; our interests, values, talents, ideas" (p. 19). Sociology theory draws on a variety of philosophical and ideological perspectives and the choice of perspective has determined the way we view dementia care and our policy response to it (Bond, 2001). One sociological view of dementia adopts the social model of disability and according to Bond (2001), focuses on the way people with dementia and their informal caregivers interpret their own experiences of living with dementia and the meaning that their situation has for them. In this view, the onset of dementia would be considered a significant life event for the individual and close family members, but is only the beginning of a new 'trajectory' within the life course (p. 48).

People with dementia are experts in their experience (Reid, 2001)

Epistemological challenges in research and care often focus on the degree to which people with dementia have insight into their 'deficits.' Insight is defined by Bond et al. (2002) as "the ability to understand one's own problems. Lack of insight then is a professional judgment and therefore grounded in the medicalization of dementia" (p. 313). Medicine has contributed to the social construction (medicalization) of dementia, which is a clinical condition applied to a diagnosis such as Alzheimer disease, with the different types of dementia socially constructed, and the differences between normal and abnormal seen as arbitrary (Bond, 2002). In a review of forty-nine texts available to medical students, these same authors (Bond et al., 2002) found through content analysis, clear indication that 'anosognosia' (unawareness), 'competence', 'confabulation', 'insight', and 'impaired judgment' are all biomedical concepts, and play a key role in the assessment and diagnosis of dementia (p. 323). Medicalization of dementia has led to the

depersonalization, loss of independence, and loss of social and political rights of people with dementia with the subsequent notion of 'blaming the victim' (Bond, Corner, Lilley & Ellwood, 2002).

From a phenomenological approach if a person with dementia was interviewed for insight into some aspect of his or her life we must recognize that he or she may be exceedingly vulnerable to being embarrassed, and humiliated (Sabat, 2002) and therefore deny symptoms. The dimensions of insight in people with dementia were recently studied by Howard and Saper (2003), by comparing qualitative and quantitative methods of assessing awareness of deficits. It was recognized by the study that a qualitative approach is necessary in order to determine the part played by psychological factors such as denial and self-concept. Research findings suggest seven psychological themes that emerge through conversations evidencing awareness, which the authors claim is hard to capture using questionnaires (one of the traditional formats for quantitative research). Quantitative measures, using scales to access insight, prioritize very different aspects of awareness, namely cognitive, at the expense of other areas which may have more of an impact on a person's ability to function in everyday life (p. 120). The following are the subjective themes of how people with dementia account for their difficulties (Howard & Saper, 2003, pp. 117-118). These themes provide valuable insight into the experience of people with dementia and are as follows:

(1) **Frustration, distress, or anger** when confronted with tasks now beyond them such as remembering an item in a piece of information.

(2) **Discontent, or upset** over their condition.

(3) **Unconcern** at an emotional level despite explicit awareness of deficits.

(4) **Normalizing** response, adopting a stoical attitude to their symptoms. For example "I've had a good life."

(5) **Worry and anxiety** often exhibited by marked signs of repetitiveness or obsessionality.

(6) **Defensiveness**, that served the purpose of minimizing or denying their deficits.

(7) **Explicit denial of problems**, although there was some awareness of respondents' deficits at an emotional level, even though this was quickly forgotten.

(8) **Priority given to other problems** (such as aArthritis) although the respondents acknowledged their cognitive and other difficulties.

The authors conclude that a comprehensive and reliable protocol for assessment of insight in dementia must include both qualitative and quantitative methods. Wilkinson and Milne (2003) concur that assessment of dementia should include an account of the patient's perspective. Even when a patient's perspective on dementia is considered there tends to be reluctance on the part of physicians and family to share the diagnosis with persons with dementia. Persons with dementia tend to be given information about symptoms and the cause is described predominantly as "part of aging" (Downs, Clibbens, Rae, Cook, & Woods, 2002, p. 47).

Fahy, Wald, Walker and Livingston (2003) recently addressed the issue on the dilemma of disclosing the diagnosis to an adult with dementia. In their study, 54 percent of 100 carers wished the diagnosis to be revealed. The results of the study by Vernooij-Dassen, Van Hout, Hund, Hoefnagels and Grol (2003) indicated that basic information about diagnosis was given to 86% of patients and 88% of caregivers. The value of early diagnosis and providing basic information about diagnosis, including the patients' perspective, is suggested as a way to avoid the need for 'secrets and lies' and the withholding of information as the dementia progresses.

A psychosocial model for understanding the experience of receiving a diagnosis of dementia was developed by Pratt and Wilkinson (2003). The different psychological processes such as noticing symptoms, the diagnostic process, the disclosure of the diagnosis, the prognosis, maximizing coping strategies, denial, and distress representing the individual's journey with dementia was discovered not to be linear as believed in the past, but very much 'individual pathways' through different stages (pp. 190-195). This psychosocial model suggests a need to examine and assess the social context of the dementia experience. The model also suggests that distress is not only caused by individual psychological reaction, but also through the negative aspects of the social context. Including the social context into a model of understanding the experience of dementia would address the impact of attitudes and approaches of medical staff, the access someone may have to information (such as a diagnosis), formal and informal support and social stigma (Pratt & Wilkinson, 2003).

Another study by Menne, Kinney and Morhardt (2002) focused on the day-to-day experience of individuals with dementia related to concerns and fears resulting from a diagnosis, behaviour changes, and relationship issues. It was strongly evident from interviews that participants communicated insight into their experiences, at least at the early stages, and were striving to maintain 'continuity' of activities by "trying to do as much as they can" (p. 379) The underlying practical and clinical implications suggest the importance of interventions such as activity groups and support groups for those in the early stage of dementia. These activities allow individuals to "preserve and maintain the longstanding social patterns of living" (p. 379).

Social patterns of living are unique to an individual and are a reflection of a person's past and present psychosocial context. According to Bryden (2002), insight into

a person's past and present psychosocial context and knowledge of coping mechanisms allows for a person-centered approach to psychotherapy and rehabilitation of people diagnosis with dementia in the early stages. According to the author, dementia can be regarded as an adaptive response to cognitive decline. The types of interventions that might be offered from this perspective include grief counselling, non-directive counselling, long-term supportive psychodynamic psychotherapy, and cognitive behavioural therapy (Bryden, 2002, p. 154).

Smyth et al. (2002) claim that interventions that treat deficit identification as an interpersonal and social challenge inherent in the experience of dementia would enhance quality of life of caregiving dyads. The authors also argue that families as a unit can be helped to develop a 'shared understanding' of the meaning of dementia in their lives and to learn strategies for maintaining meaningful roles and relationships early in the illness in spite of deficits (p. 345). Current research appears to still focus on skill-building groups for family caregivers only (Perraud, Farran, Loukissa, & Paun, 2004) ignoring the person with dementia.

Carers are experts in their situation

Experienced care givers, many of whom have learned their skills and expertise by trial and error often have a far better grasp of their situation than professions (Nolan & Keady, 2001) and are considered experts in their own situations (Nolan et al, 1996). A recent study by Gaugler, Zarit, and Pearlin (2003) provides insight into 'carers as experts'. The authors focused on the patterns of entry into the caregiving role and resulting influences on outcomes longitudinally. One of the consistent findings throughout the study, using three year longitudinal data, was that those caregivers who

experienced a less abrupt transition to care (i.e., care provision over a longer period of time prior to diagnosis) were less likely to place their relatives, or experience poor adaptation over time. These caregivers appeared well-entrenched in their responsibilities prior to recognition of dementia symptoms or a professional diagnosis. This finding is contrary to earlier postulations that the longer the duration of care, the more likely the care provider would suffer from psychological and emotional distress. The authors claim "that a certain adaptation occurs among long-term caregivers" (p. 12). As well, it is suggested that future research on the construction of role in caregiving relationships should be based, not only on the caregiver's expectations, but also on the care receiver's (Gaugler, Zarit, & Pearlin, 2003).

Bowers (1987) developed a typology of intergenerational care for people with dementia in an attempt to more adequately understand the experience of the carer. Her typology of care forms the underpinnings for a holistic (multidimensional) model of understanding family care reported on in more recent literature on the subject. Bowers suggested that much of the work of caregiving is 'invisible' in that it does not include overt behaviour task care and is not apparent to the cared-for person (Nolan & Keady, 1996). Instead, a delicate dynamic process of negotiation occurs in which family history and biographies interact, resulting in the "development of commitment over time" (p. 53). Family commitment to care led to Bowers creating a typology of five distinct but overlapping kinds of care:

(1) ***Anticipatory care*** – this is based on anticipated future needs, with the key notion being 'just in case.' Anticipatory care can begin many years before any actual help is required and is deliberately kept from the person who is the focus of attention.

(2) ***Preventive care*** – the main component of this type of care is 'monitoring at a distance.' Again the 'cared-for-person' may remain largely unaware of its existence.

(3) ***Supervisory care*** – when a 'monitoring role' requires direct intervention, such as assistance with taking medication, supervisory care has been reached. At this point, the cared-for-person is more likely to be aware of the interventions, but the carer may still try to minimize such awareness.

(4) ***Instrumental care*** – as the need for direct assistance increased and the carer has to 'do for,' then this stage has been reached. The cared-for person is now largely aware of his/her need for help but carers will often try to maintain an element of reciprocity in the relationship (often viewed by carer as least stressful although most earlier research and interventions focused on this type of care).

(5) ***Preservative care*** –Preservative activities by staff are intended to help maintain a family connection and include maintaining dignity, hope and a sense of control for the cared for person in the family's absence.

Nolan, Grant and Keady (1996) built on to Bowers' typology two additional broad care types considered to have a temporal relationship, (re)constructive care and reciprocal care. The authors believed that the main adaptive task in chronic illness or disability is to develop new but equally valued roles to replace former ones. Within this context, protective and preservative care, although considered well meaning, could be viewed as paternalistic and would not best serve either carer or cared for person over time. It is here that (re)constructive care was configured.

(6) ***(Re)constructive care*** – the purpose of this type of care is to build on the past to develop new and valued roles, to rebuild a new identity on the foundation of past histories and biographies. The authors argue that a "need to 'construct' an acceptable future is pressing" (p. 45).

(7) ***Reciprocal care*** – refers to opportunities for reciprocal elements in the caregiving relationship that can be viewed from a number of different levels. The authors believe that reciprocity and satisfaction should be seen as the norm in most caregiving relationships and that these can be sustained even in the face of objectively adverse circumstances. They warn that the absence of reciprocity and satisfaction should act as an indicator of the need for additional support of services (p. 45).

During the early 1980s Wilson claimed that it was not possible to design appropriate interventions until there was a better understanding of the carer's rationale for the coping strategies they used (Nolan et al, 1996). Her conceptualization of stage-specific coping approaches that included noticing; discounting/normalizing; suspecting; search for explanations; recounting; taking it on; going through it; and turning it over; provided a framework for elaboration in the 1990s and beyond not only for caregivers, but for cared for persons as well (see, for example, Keady's coping strategy of 'making sense of the situation,' 1999). A recent phenomenological approach (the lived experience within context) was used to capture this strategy in the study of the unique aspects of the experience of older women caring for their spouses with Alzheimer's disease at home 'making sense of the situation' (Paun, 2003). Unlike other studies, the women in this study reported that they did not express anger and resentment towards their spouses even in 'less than perfect marriages' nor did they perceive themselves as victims.

In a larger phenomenological approach (Butcher, Holkup, & Buckwalter, 2001), a sample of family caregivers (n=103) was studied and the experience of caring was analyzed, forming eight structural elements: (1) being immersed in caregiving; (2) enduring stress and frustration; (3) suffering through losses; (4) integrating Alzheimer disease and related dementias into our lives; (5) preserving integrity; (6) gathering support; (7) moving with continuous change; and (8) finding meaning and joy (p. 33). The authors claimed that 78% of caregivers managed to find both positive aspects and meaning in the caregiving process. Meaningful and joyous times were created through the recollection of earlier and happier memories, engaging in pleasant activities enjoyed together, cherishing the preciousness of the immediate moment, and remaining loyal to the commitment to one another (p. 51).

Working with family carers of people with dementia

According to Nolan, Ingram, and Watson (2002), supporting family carers is likely to remain at the forefront of community care policy in dementia care for the foreseeable future, as global aging continues and government responds with policies to support community living (often to reduce costs). Kileen (2002) suggests that carers of people with dementia must have the opportunity to be involved in service developments instead of being expected to "fit into fairly bureaucratic planning structures in which they have felt disempowered" (p. 281).

Nolan et al. (2002) suggest a re-appraisal of the ways in which a successful intervention is defined, and promote the partnership approach in which carers play a significant role in what works. These authors suggest that "if what works well in families is not recognized, the risk of inappropriate interventions from services will remain high" (p. 88). Given the central importance of the quality and history of the dyadic relationships between the person with dementia and the caregiver, interventions that foster improved communication between the dyad will be critical (Nolan, Ingram, & Watson, 2002).

The marriage "relationship-biography"

"I just feel that this is the least I can do for him, because we do care for each other."
(Butcher et al., 2001, p. 49)

Marriage is defined as a close union. Good or "loving" supportive marriage histories have been known to enhance perceptions of well-being for both men and women (Spitze & Ward, 2000; Mookherjee, 2001). On the other hand, difficult or "bad" marriage histories have been known to undermine the psychological well-being of a couple (Kristi, 2003). However, Paun (2003) found a relentless commitment to provide dementia care at

home in spite of difficult past relationships, which she attributed to the meaning attached to the marital bond. A marriage bond is a covenant, a binding agreement. That agreement refers to a duty, promise, or obligation of a couple to each other, "in sickness and in health." Caring for a life-long partner is simply part of the marital bond for many older married couples (Perry, 2002).

A marital relationship implies that two people, a couple, interact with each other and with their environment over the course of a shared life together. A couple's experiences will include times of happiness and contentment, but also times of difficulties and distress (Wright, 1993). When the distress is Alzheimer disease in one spouse, the couple's interactions will undergo change. For both spouses, "the long-term marital relationship is the most important context for continuing interactions" (Wright, 1993, p. 6). Robert Atchley (1989) suggests that as people age they return to familiar behaviours and roles wanting to maintain *continuity* to the marriage relationship. Continuity Theory assumes evolution, not homeostasis, and the assumption allows change to be integrated into one's past history without necessarily causing disequilibrium. Atchley argues that continuity is a 'preferred strategy' for dealing with aging as both internal and external continuity help individuals focus on and maintain their current strengths and minimize the effects of deficits as normal aging occurs. "Older people reinterpret their current experiences so that old values can take on new meanings appropriate to present circumstances" (p. 187). Chalmers and Milan (2005) reported on marital satisfaction during the retirement years from data in the 2001 General Social Survey. Findings suggested that older married couples (aged 50-74) generally rate the quality of their relationship highly and the older the men and women are, the more likely they are to feel positively about their relationship.

Several studies have looked at the impact of dementia on the marital relationship. Kramer (1993) found that the quality of the relationship prior to the onset of dementia was an important predictor of quality of life, caregiver satisfaction, and depression in wife caregivers. In the presence of Alzheimer disease, Wright (1993) found that caregiving spouses carried the majority of major household responsibilities alone, and often used tension control and displacement as ways of dealing with emotional strain. Her findings suggested that caregivers clung to the image of the spouse with Alzheimer's disease as a valued person. The author described the couple as "two people living together, each in different worlds of awareness yet unable to leave the relationship" (p. 12). Similarly, Norman, Redfern Briggs and Askam (1994) examined the perceptions and management of change by people with dementia and their caregivers living at home. The main categories of change to emerge in the data were change in normal routines and practices in day-to-day living. Change was perceived, on the whole, in negative terms for both the caregiver and person with dementia. In this study people responded to change by making positive comparisons, by attempting to understand it, or by acceptance. In these ways couples sought "continuity or a sense of stability and security" in the face of deteriorating and unpredictable disease (p. 38).

Lewis (1998) researched how caregiving spouses fashioned the present experience of dementia in light of past events or how memories were used. The results of the study suggested that spouses interpret their present experience in the context of their whole lives. The way spouses use their past affects their current perceptions and experience of caring. The marriage relationship (biography) served as a benchmark for 'what happened' when the challenge of dementia arose. Spouse carers have meaning systems in their interactions with their spouses which have been formed and refined over

the years. Their present role and their motivation to care can be seen in the context of their previous relationship, regardless of whether it was close and compassionate or not. The spouse saw it as "reciprocation for the love and affection he/she had shared with a spouse with whom he/she felt an emotional bond" (Lewis, 1998, p. 228).

Perry (2002) found that wives who care for husbands with Alzheimer's disease constructed new daily lives to sustain the relationship. Wives would "rewrite identities" for their husbands that incorporated the dementia and rewrite identities for themselves to reflect their new roles, abilities, and strengths. This allowed for positive aspects of caring to be considered along with grief and frustration. In a large U.S. national collaborative Alzheimer's disease caregiver study (n=1,229) (Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004), caregivers reported that caregiving made them feel needed, useful, and good about themselves.

Relationship difficulties were studied by Forbat (2003) using discursive analysis to explore the power of language in instructing and communication accounts of dementia care and relational difficulties. Discourse analysis suggests that "language is used actively to construct versions of the world" (p. 70). The author suggests that accounts of longstanding tension which, although not caused by dementia, seem to be exacerbated by it. Forbat found that eliciting talk about people's pasts allowed room for the construction of narratives that explain the current relationship. She suggests that this approach may have utility when used with people who have a long-shared history – for example, in intergenerational care dyads. Two histories can be seen as interacting story lines rather than separate narratives (p. 81). Cayton (2004) challenges us to consider the role of narrative in the lives of people with dementia and to envision illness as a continuation of their story, not its ending. Further, Cayton suggests that we need to see the diagnosis as

the 'once-upon-a-time' of an illness, the start of a story (p. 10), not the end. Personal narratives are similar to oral histories, personal histories, and case histories, and therefore according to Riessman (1993), "meaning-making structures which are created, structured and authored" (93). Narratives are then widely used to create and interpret self in face-to-face interactions, suggests Mills (1998). She further suggests that personal experiences form part of a person's life story, and that self story stands alone, but is always constructed "embedded in a culture, ideological, and historical context" (p. 43).

Summary

Each different perspective of scientific understanding (biomedical, psychological or sociological) has its own language and way of telling its part of a story and interpreting it as truth (Cayton, 2004). From a sociological perspective, dementia and dementia care is very much a "social state of affairs" and is perceived differently by the person with dementia, informal caregivers, health professionals and society (Bond, 2001, p. 50). Social science research on dementia has generally been framed by the biomedical framework and reinforced by social services that assume irreversible decline through a series of stages characterized by normative symptoms (Gubruim & Sankar, 1994). However, diagnosis has been a significant act in the practice of medicine as "without diagnosis there is no meaning to our illness, and without diagnosis there can be no proper treatment" (Cayton, 2003, p. 10). As a result of this view, the person with dementia such as Alzheimer's disease, is one of domination by the disease while his or her lived experience is essentially ignored. The view of the person with dementia has seldom been considered mainly because it was believed that they were not capable of expressing it. There is a rising interest in the role of autobiographical memories, that aspect of memory

deemed to contain emotional memories of the personal past (Mills, 1998), that are highly available for recall and comparatively resistant to being forgotten (Conway, 1990), particularly in the early stages of dementia.

It is evident that dementia and dementia care mean different things in different contexts as we are not challenged with a problem simple of easy to understand (Cantley & Smith, 2001). Improved interventions do not exist in the search for strong enduring predictors of stress and burden of need, but in skillful assessment (Nolan, Grant & Keady, 1996). The complexity and uniqueness of caregiving is best captured in an approach that integrates concurrent conceptual ideas which focus on relationship-centered care. Marriage relationship-biography fits with the approach of relationship-centered care. The significance of considering the marital dyad as living-in-relationship with respect to dementia is: (1) a marker of a couple's commitment to each other through their marriage 'in sickness and in health'; (2) a marker of their strengths and weaknesses in dealing with other life challenges to ascertain capacity to care; (3) an indicator of areas in the marriage biography that could form the basis for problem identification and thus a counselling guideline; and (4) a barometer of outside support required.

Marriage biographies are retrospective (past memories) and prospective (present situation) reflections. Emotional intersubjectivity in marriage creates a biography with a shared view of reality that is altered by dementia, creating new social relations in marriage referred to in symbolic interactionism as 'joint production of meaning.' A new reality is then socially constructed to help make sense of the situation. The process of reappraising and reconstructing meaning continues throughout changes to the marriage relationship, roles and responsibilities well after a diagnosis of dementia. While researchers seek answers as to the capacity of couples to provide care, they may very well

find the answers to these questions located in the past – in the quality and history of relationship-biography in general and marriage relationship in particular.

Chapter Three

Methodology

Introduction

The purpose of the research study was to gain a better understanding of couples' commitment to their marriage relationship, and how that commitment influenced the experience of dementia. Understanding how couples interpret and enact the impact of their commitment to each other and to their relationship historically and contextually became the vehicle for understanding the impact of their commitment in relation to a diagnosis of Alzheimer's disease. Social constructionism was the epistemology theory of knowledge embedded in the theoretical perspective symbolic interactionism that acted to inform the narrative analysis and provided a context for my study. Based on the principles of naturalistic interpretive research paradigm, I used a "dual research strategy" by blending qualitative interviews with quantitative measures (Cheung, 1999, p. 47). I conducted in-depth qualitative interviews with couples in long-term marriages where one spouse was diagnosed with early stage Alzheimer's type dementia, to understand how these couples achieved integrating dementia into everyday life. Narrative analysis is the method I adopted to analyse narrative themes and meanings in couples' recalling of their stories about their commitment over their thirty or more years of marriage. Oliver (1998) states that because people give meaning to their lives through the stories they tell, and the marriage biography is a central narrative in the lives of spouses, it is appropriate to study human experience with research methodology that connects with how people construct meanings in their life experiences.

This chapter begins with my rationale for using both qualitative and quantitative methods under a naturalistic/interpretive paradigm. I then discuss researcher bias and the role of reflexivity. Combining qualitative and quantitative data provided me with additional insight into the marriage relationships not captured using a singular approach. Second, I present a review of symbolic interaction(ism) as the conceptual basis for narrative analysis. Third, I present the selection criteria for couple respondents. Fourth, I describe the recruitment and data collection procedures. Fifth, I discuss the narrative analysis methodology. Included in this section are my techniques for joint interviewing of couples. Finally, I discuss the trustworthiness of my research findings.

The blending of qualitative and quantitative methods

Mixed-methods research design involves the collection, analysis, and integration of qualitative and quantitative data in a single or multiphase study (Hanson et al., 2005). Quantitative and qualitative data analysis are often seen in conflict and undertaken as separate enterprises as they emerge from different philosophies of science. Researchers from both realms often rely on triangulation procedures, in which each is considered from its representative lens; data are melded and discussed from both perspectives (Wendler, 2001). The concept of triangulation was first used by Denzin (1978), and is a term borrowed from navigation and military strategy, to argue for the combination of methodologies in the study of the same phenomena. The concept was based on the assumption that any bias inherent in particular data sources, investigator, and method would be neutralized if used in conjunction with other data sources, investigators, and methods (cited in Creswell, 1994, p. 174). Green, Caracelli, and Graham, (1989) derived the following five purposes for mixed-methods studies:

(1) Triangulation: to determine convergence of results;

(2) Complementarity: to examine similar and different aspects of the results;

(3) Initiation: to reveal fresh perspectives;

(4) Development: to use sequential methods where the primary results inform the second method;

(5) Expansion: to add breadth and scope to knowledge of the phenomenon (cited in Creswell, 1994, p. 175).

The addition of the following quantitative scales was used for the purpose of triangulation to provide a more complete understanding of the marriage relationship; the Dyadic Adjustment Scale (DAS) (Spanier, 1976), to measure marriage adjustment; the Role Orientation (ROR) subscale of the Marital Satisfaction Inventory to determine gender role expectation in marriage; and the Commitment to the Spouse (Swensen & Trahaug, 1989) to measure spousal commitment to marriage. These scales were intended to be administered to both spouses. However, two spouses were not able to complete the scales on their own and decided to complete the scales as a couple. A sequential exploratory design[5] was used, in which qualitative data were analyzed first, followed by quantitative data (although it was collected first) (Hanson et al., 2005). Silverman (2005) provides some useful strategies appropriate for qualitative data that fit with the purpose of my research study. He outlines five situations when it is an advantage to use qualitative data:

- Asking 'how, 'what' and 'when' and delaying (or avoiding) 'why' questions.

[5] Sequential exploratory designs do not use an explicit advocacy lens. In this design, qualitative data are collected and analyzed first, followed by quantitative data. Priority is usually unequal and given to qualitative data. Quantitative data are used primarily to augment qualitative data. These designs are useful in exploring relationships when study variables are not known, refining and testing a emerging theory and generalizing qualitative findings to a specific population (Hanson et al. 2005, p. 229).

- Whenever possible (and it usually is possible) working with naturally occurring data.

- Studying the categories actually employed by the participants (and when and how they are used – and what effect.

- Studying what is remarkable, the routine and the 'ordinary'.

- Recognizing the interconnectedness of subjects' categories and of their activities so that we always study how each is laminated upon another (p. 349).

Several of these situations were relevant to my research study. My questions focused on when, how, and what events of the couples' marriage biographies. I studied the categories actually employed by the spouses and how they were used, for example, 'doing things together' and 'working through difficulties'. I wanted to understand the routine and the ordinary, the experience of integrating dementia into everyday life. My final model recognized the integration and interconnectedness of the global theme *marriage is a partnership for life*. Both qualitative and quantitative data analysis were connected and integrated at the data interpretation stage and in the discussion.

Contribution of combining scales and interviews to the research findings

Combining the quantitative scales with the interviews increased the quality and scope of the research findings. I was able to witness the challenges couples faced in working on tasks separately during the first home visit when the couple filled out the questionnaires. It was at this time I was provided with additional insight into the level of disorientation of the spouse diagnosed with Alzheimer's disease. If the level of confusion was high, a couple worked on the questionnaires together.

The scales provided separate accounts of a spouse's marriage satisfaction and quality in an objective way. The scales also asked questions relating to sexuality and marriage happiness that provided new insights for data analyses. These separate accounts provided complementary information in support of the couple's commitment to their marriage relationship. I was also able to compare scores across couples looking for similarities, differences, and inconsistencies relative to marriage commitment, and the dementia experience.

Theoretical sensitivity

The goal of most qualitative research is to learn from the data, but in all social research, qualitative or quantitative, the researcher brings into the project his or her own sensitivity in the form of personal values and commitment to his or her topic (Richards, 2005). I believe my understanding of the multiple dynamics of dementia and its impact on couples and their families enhanced my awareness, knowledge, and sensitivity to many of the challenges facing spouses experiencing dementia and assisted me in working with the information in the study.

I bring certain sensitivity and insight to the phenomena of interest in this study. This sensitivity and insight shape the way I view and understand the data I collected and the way I interpreted my experiences. I viewed an understanding of the quality of the couples' marital relationship as critical at the time of diagnoses of dementia. I view the early dementia experience to be filled with adjustments, frustrations, unanticipated surprises, and challenges. I also view the early dementia experience as a time when couples have the opportunity to plan and re-evaluate their commitment to each other and move on to a new chapter in their married life.

The role of 'reflexivity' in qualitative research

Qualitative research is about agency. Researchers make data and work with data and in the process need to reflect on their own data-making role. This process is referred to as 'reflexivity' and is described as an acknowledgement of the role and influence of the researcher on the research project. With this process the role of the researcher is subject to the same critical analysis and scrutiny as the research itself (Coralan, 2003). Thinking about reflexivity alerted me to the biases I took to the project, as well as the fact that I am part of the study (Richards, 2005), as data are made collaboratively by the researcher and the researched. Upon reflection of my role and influence on the study, I am aware that my background and experiences as a nurse and social worker, together with my philosophical stance, values, and feelings, have contributed to my interest in the area of dementia generally, and marriage commitment specifically and have influenced the analysis of this study. I acknowledge that I believe spouses do 'the best they can' in their situation of Alzheimer's disease and are often very resilient to challenges presented by the disease.

Symbolic interaction (ism): Values and beliefs

The work of George Herbert Mead (e.g. Mind, Body, and Self, 1934) is most often given credit for the emergence of symbolic interaction, focusing on the key concepts of *self* and *mind, socialization, role*, and *definition of the situation.* Central to this approach is the idea that "by sharing common symbols, humans can adapt to and survive their environment" (White & Klein, 2002, p. 16). Blumer's addition of "ism" to the end of interaction reflects the dynamic processes of cultures and people as they

continually strive to define, and re-define the context and meaning of actions (Keady, 1999).

There are a number of beliefs and values inherent to understanding symbolic interactionism (SI) as a perspective. Charon (2004) identifies five central ideas.

1. *The role of social interaction.* Symbolic interaction focuses the nature of social interaction, the dynamic and social activities taking place among actors. Interaction means that the acts of each individual are built up over time, depending in part what others do in a situation in relation to them. *Social interaction is almost always central to what we do.*
2. *The role of thinking.* According to SI, we act according to how we are thinking in the specific situation we are in, although we may be influenced by our interaction with others. *Thinking is always central to what we do.*
3. *The role of definition.* According to SI, we act according to our definitions. As we interact with others and ourselves, we develop our definition of what is taking place in our situation, and how to act in that situation as we have defined it. The reality that exists "out there" is far less important than our definition of reality. *Definition is everything: what we do does not result simply from reality as it is but how we define what it is.*
4. *The role of the present.* According to SI, our actions result because of what is occurring in the present situation. Our past enters in because we think about it and we define it in the present. *The present, not the past, must be understood in order to understand cause; what is going on right now in our present situation makes the real difference in how we act.* (Charon, 2004, pp. 28-29).

5. *The role of the active human being.* According to SI, we *use* our environment rather than respond to it, *define* our environment in relation to our goals in the particular situation rather than act as passive products of the environment, define our past in terms of the present as caused by the past. *We are here conceptualized as active participants* in what we do, even perhaps "free," at least to some extent.

Framing a Selected SI Vocabulary

Canfield (2004) suggested that a vocabulary associated with SI has been developed over many years. Major concepts include the following:

I – the proactive part of self enactive and agentive.

Me – the sensitive, reflexive, more durable part of self.

Self – a combination of I and Me in Median theory, created through interaction. The self is seen as a symbolic object.

Play – social activities in which children take part, but which are microcosms of later social life.

Sensemaking – the interpretive activity of creating meaning of self, others and interactive behaviors.

Role-taking – the ability to put oneself in the place of another; an intersubjective and shared understanding are the result.

Symbol – the semantic representation of the objects in one's life, whether they are physical, psychological or social, considered the building blocks of meaning.

Mind – a dynamic, socially oriented, behavioural and processional entity that enables humans to make sense of behaviour and act accordingly.

Agentry – the ability of humans to enact lines of action on their own behalf to adapt to their own social circumstances.

Joint production of meaning – refers to the fact that humans cooperate and participate in actions, creating new social relations.

Frames of reference – perpetual lenses based on personal experiences that help people interpret human behaviours. (Canfield, 2004, p. 153)

Three major influences are considered to be central to all symbolic interactionsists; (1) the philosophy of pragmatism; (2) the work of Charles Darwin; and (3) behaviourism (Charon, 2004). George Herbert Mead is considered to be the originator of the main concepts in the perspective of symbolic interaction.

Pragmatism, considered a school of philosophy, presents four important ideas to Mead's understanding of the nature of truth as Charon (2004) explains. First, pragmatists examine the human relationship to the environment, contrasting it with the relationship of other animals to their environments. *What is real for human beings, it is proposed, depends on our active intervention, our own interpretation or definition* (p. 30). Second, pragmatists try to explain what knowledge is, what we believe and remember. *To the pragmatist, knowledge is judged by how useful it is in defining the situation we enter* (p.31). Third, pragmatism tries to explain how we actually see or notice objects in our environment. *Things in situations are defined according to the use they have for us at the time* (p. 31). For example, a wastebasket can be used for trash, to store articles, or practise basketball; the intent depends on the actors' goals. Fourth, pragmatism tells us something about how philosophers and social scientists believe they should study human

beings. *Start with action. It is what human beings do in real situations that matters* (p. 31).

Charles Darwin, creator of the theory of evolution, a theory that focused on the development of the various species of animals, was considered a naturalist and believed "that we should regard the human being in naturalistic terms" (Charon, 2004. p. 32). Mead agreed with the evolution process of animals, but believed that once humans formed they were able to use language, and in time began to reason "we were able to turn our back on nature itself, actively directing how the natural forces act" (p. 32). These ideas led Mead to believe that the individual was a dynamic changing actor, always in the process of being socialized. Society, as well, was not considered static, but a developing process characterized by continuous ongoing interaction. Mind, to Mead, was action, and whatever self we had is also a process. Change was also a common theme. Mead believed that truth changes; our symbols change; our rules change; our use for the environment changes and "what we are today is different from what we were yesterday or even one moment ago" (Charon, 2004, p. 33).

The other influence for Mead was from the school of psychology called behaviourism (Charon, 2004). A behaviourist would claim that the best way to understand animals, including humans, would be to carefully observe their behaviour. Mead referred to himself as a "social behaviourist" because he believed behaviour included action that is not directly seen, action that takes place in the actor, action called 'thinking' or 'minded action'. This led Mead to believe that, without an understanding of mind, symbol, and self, human behaviour could never be understood for what it actually was. The key ideas influenced by pragmatism, Darwin, and behaviourism are central to the perspective of symbolic interaction assumptions: *that communication, both verbal*

and nonverbal, requires the use of shared symbols; that self and identity are constructed through interaction, and that humans create society through interaction (Canfield, 2004, p. 152).

Erving Goffman, a sociologist who wrote after the middle of the last century, contributed the 'dramaturgical' perspective to symbolic interaction (Canfield, 2004). From this perspective ,Goffman viewed social life as something like a staged drama (Charon, 2004). The two characteristics of social interaction, drama and ritual, were considered complementary to Goffman, and both were implicated in the "collaborative manufacture of selves" (p. 177). This idea is relevant to understanding relationship situations that people with dementia face in trying to interact in the 'best way they know how.' Goffman, as well as many others before him, viewed "self" as a prominent underpinning of symbolic interaction. Goffman viewed "self" as something that must be produced anew on each and every occasion of social interaction. For Goffman, the individual "must rely on others to complete the picture of self" that his or her performance outlines (for example, many people with dementia must rely on their caregiver). In other words, others fill in and sometimes reshape that outline of self through their actions toward the individual (p. 180). Through the respect or lack of respect others show us, argues Goffman, we are "instructed" what we must or must not do to gain their cooperation in construction of a socially acceptable self. In his very influential book, Asylums, Goffman (1961a) illustrates how environments in total institutions (social control), such as mental hospitals and nursing homes, socially stigmatize patients, resulting in their loss of self and self-concept. Their only hope of gaining some rights and liberties (and to save face) is to accept the hospital or nursing home's conception of them as 'ill' (Charon, 2004, p. 186).

Four variations of symbolic interactionism have evolved since Mead's death; the structural approach, the interactional approach, the microinteractional approach, and the phenomenological approach (White & Klein, 2002). The phenomenological approach has been used in studying family caregiving and dementia, and the microinteractional approach has been used in studying the experience of persons with dementia.

Assumptions

Symbolic interactionism provides several logical assumptions that are 'conditions for this study.' That means they are assumed to be true and taken for granted. Herbert Blumer, a student of Mead's, provides these three basic interactionist assumptions:

- *that human beings act toward things on the basis of the meanings that these things have for them;*
- *that the meaning of such things is derived from, and arises out of, the social interaction that one has with one's fellows;*
- *that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters.* (Blumer, 1969 cited in Crotty, 1998, p. 72).

In SI the role of past experience and history is used to define the present. Significant others, reference groups, perspectives, beliefs, decisions made, situations experienced, and information from our past are recalled, and used as social objects to work through the present situation (Charon, 2004). What we know and remember is applied to situations we encounter. Symbolic interactionism is an appropriate perspective to use in the study of marriage and dementia. Couples interact within marriage constructing symbolic realities based on shared meaning. Canfield (2004) suggests that partners in a dyadic relationship "define their relationship as a symbolic baby, something

they created together, existing separately for each of the individuals with an implicit set of rules, and a definitional frame for the relationship" (p. 52).

Marriage is defined as a 'close union'. Good or loving and supportive marriage histories have been known to enhance perceptions of well-being for both men and women (Mookherjee, 2001). On the other hand, difficult or non-supportive marriage histories have been known to undermine the psychological well-being of the couple (Williams, 2003). Paun (2003) found a relentless commitment to provide dementia care at home in spite of difficult past relationships, which she attributed to the positive meaning attached to the marital bond. A couple's interaction pattern, their expectation of commitment in marriage, roles, responsibilities, and their decision making processes, as well as the meaning they attach to a situation, all help us to understand their marriage relationship.

Selection criteria for couple respondents

I selected six long-term married couples referred to me from a memory assessment clinic who volunteered for in-depth joint interviews (each couple was interviewed separately). Married couples were selected for the study based on the following criteria:

- Respondents had to be heterosexual married couples who were 60 years of age or older, in a marriage considered 'long-term' (20- 30 years) and one spouse had to be formally diagnosed with early-stage Alzheimer's disease.

Rationale

According to Statistics Canada, marriage is the foundation for most Canadian families. For example, in 2002, about 84% of Canadian families were headed by married couples. The religious sanction of marriage remains important to many Canadians.

Members of clergy conducted three-quarters of all weddings in 1997. Religious weddings were most common in Ontario. By contrast, more than half the weddings in British Columbia were civil services.

The symptoms of Alzheimer's disease usually only become evident after age 65, however, they may occur as early as age 40 (in rare cases, even younger). The risk of Alzheimer's disease doubles every year beyond age 65 (Mittleman, Epstein, & Pierzchala, 2003).

- The couple had to use English as their main language, be able to read and write English, and had to physically and mentally be able to become respondents (not visually or hearing impaired), and the spouse diagnosed with Alzheimer's dementia had to be willing and able to make informed consent.
- The spouses had to agree to the completion of demographic information such as age, number of children, years married, etc., and the following scales: the Dyadic Adjustment Scale (DAS) (Spanier, 1976), the Role Orientation subscale (ROR) of the Marital Satisfaction Inventory (Snyder, 1989), and Commitment to the Spouse (Swensen & Trahaug, 1985).
- The spouses had to agree to the terms of the informed consent and sign it.

My definition of long-term marriage is one in which the couple has been married for twenty years or more (Sharlin, Kaslow, & Hammerschmidt, 2000), although most of the empirical studies on long-term marriages sample couples married thirty years or more (Cheung, 1999).

The goal of the research was to document how couples enact their marriage commitment in the dementia experience. Saturation of data occurred after six couples had been recruited. For my study, I was not concerned about size and representativeness

of the sample as it was exploratory in nature. According to Glaser and Strauss (1967), sampling should proceed until the collection and analysis of new cases adds little insight to the phenomenon under study. At that point 'saturation' occurs, and further sampling is unnecessary (cited in Gubrium & Sankar, 1994).

All participants were recruited after one of the spouses had been diagnosed with Alzheimer's type dementia in the early stage, and both married spouses had been informed of the diagnosis. This was not an issue as all referrals were patients involved in a clinical drug trial where disclosure of diagnosis was imperative. I made two home visits and at the second home visit I interviewed each married couple. Each visit lasted approximately one and a half hours. I selected the early stage of Alzheimer's type dementia because from my experience the spouse diagnosed at that stage would be able to participate in the interviews, and sign and understand the intention of the information in the informed consent.

Ethics approval, recruitment, and data collection procedures

The research protocol (#P2005:080) received human ethics approval by the Psychology/Sociology Research Ethics Board, University of Manitoba, on December 9, 2005. Recruitment strategies included mailing invitation letters to four specialist physicians working in the area of dementia diagnoses. These physicians were located at facilities which make a dementia diagnosis based on the "gold standard"[6] criteria. These physicians were asked to locate potential couples who met my selection criteria for

[6] Although dementia of the Alzheimer's type is diagnosed by excluding other causes, an 85-95% diagnostic accuracy can be achieved by using the NINDS-ADRDA criteria (Diagnostic Standard Alzheimer's Disease Related Dementia Assessment). These criteria require the presence of the dementia syndrome and a pattern of progressive decline in short term memory (the earliest symptom) followed by impairments in comprehension, naming, visual and special abilities, judgment, insight, and organizational skills, and the ability to perform complex tasks (Institute for Brain Aging, 1996).

participation in the study. When I followed up with my first telephone contact, I was told that one physician, a neurologist I had mailed an invitation letter to and had worked with in the past, was in the process of setting up a private memory clinic and would be the most appropriate person to speak with because he would be running all early stage clinical drug trials for Alzheimer's disease from his clinic. I approached him by phone and he agreed to participate and do "whatever he could to help me out." I had mailed him an invitation letter (Appendix A) that included a contact information sheet. He informed me that he was currently involved in a drug trial with early-stage Alzheimer's disease but that recruitment was almost over for that particular trial. He arranged for a meeting and tour of the clinic and we decided that the clinical nurse, and drug trial coordinator with whom I had worked closely in the past, would help me recruit participants once the new trial started approximately three months from our meeting. That was the main reason recruitment took so long, as I had to wait until the startup of the new trial. The clinic nurse informed couples she believed met the criteria for the research project and handed them my introduction letter (Appendix B) if they appeared interested. She then called me and provided me with the couples' names and I then phoned them. In all but three referrals, I was able to arrange home visits to discuss the project and the couples then became my study participants. In the meantime, I was given contact information for the Campbells, who were interested and agreed to hear more about the project. They had been recruited from the soon-to-end drug study and became my pilot study couple, and became participants in the study.

Two home visits were made as scheduled for each couple (I made three visits for the pilot study only). The first home visits lasted one and a half hours. I telephoned the couples prior to my visits to make sure they were expecting me and nothing unusual had

come up so that we would have to reschedule. The next visits lasted for one and a half hours.

The first home visit

The purpose of this visit was to introduce myself and the research project to find out if the couple was interested in becoming participants and whether they would make good participants, that is, whether they were able to talk openly about their marriage and complete the questionnaires. Participants in the study were volunteers and were not provided with any compensation for their participation. Once the couples agreed, and the spouse with dementia deemed competent to sign, they were asked to sign the consent form (Appendix C).

The intent of informed consent requirements in social science is to protect vulnerable people (Gubrium & Sankar, 1994). For this reason, spouses with dementia may be viewed as vulnerable people and inappropriate research subjects. Individuals for this study had to be capable of giving informed consent on their own behalf. The following is the process I used to gain ethical approval for my project because half of my participants, the ones diagnosed with Alzheimer's disease, were deemed vulnerable people.

Procedure for informed consent

Competency for informed consent: "Capacity to decide"

I used a two-step process to assess competency of prospective individuals diagnosed with dementia to give informed consent based on the following rationale.

According to the *Ethical Conduct for Research Involving Humans* (2003), competence refers to "the ability of prospective subjects to give informed consent in

accord with their own fundamental values. It involves the ability to understand the information presented, to appreciate the potential consequences of a decision, and to provide free and informed consent. It does not require that prospective subjects have the capacity to make every kind of decision (p. 29).

Capacity may also be referred to as "competency," and refers to the rational-cognitive model usually adopted in legislature (Molloy, Darzins, & Strang, 1999). The definition of capacity is determined by the legal definition of capacity in each particular jurisdiction. A declaration of incapacity is serious. It removes a fundamental freedom and right to make choices for one's own life. "People should only be declared incapable or incompetent when it can be firmly established that they lack the ability to make decisions and are at serious risk because of capacity" (Molloy et al., p. 6).

The earliest clear cut deficits for individuals diagnosed with mild symptoms of dementia of the Alzheimer type include such things as confusion and memory loss, disorientation, such as getting lost in familiar places, problems with routine tasks, and changes in personality and judgment (Gwyther, 1985). When a person is clearly capable or incapable, it is easy to reach a judgment. Problems occur when individuals have partial understanding, and capacity lies in the "grey areas" between the extremes. These individuals are borderline, "probably or possibly" capable.

The individual in the couple diagnosed with dementia would not be considered if he/she was considered in the "grey area" but clearly *capable* of making the decision to become a research participant. In order to assess capacity, I assumed the generic criteria for capacity established by Molloy, Darzins, and Strang (1999) that a capable person:

1. Knows the context of the decision at hand
2. Knows the choices available
3. Appreciates the consequences of these specific choices.

Prior to the couple reading the consent form I reviewed the content with them and then left the couple on their own to each read it over. To determine eligibility for the spouse with Alzheimer's dementia to give informed consent, the following steps were taken:

Step 1: I read the "Recruitment Script" (Appendix D) indicating that if I believe that either one of them was not clear about the research purpose or process, I was obligated to not consider them as participants for the project.

Step two: I had each spouse read over the consent form carefully and then asked the following questions (decision to participate questions): (1) Now that you have read the consent form, do you have any questions for me about what you have read? (2) Are you still interested in taking part in the research project about your marriage with your husband/wife? If the spouse answered "yes", I went on to ask "capacity to decide" questions as follows: (1)What do you understand the research project to be about, that is, what does it require you to do? (2) What are your expectations of what will happen during the interview? (3) If you don't want to answer a question, is that ok? (4) Are there any consequences to deciding not to participate? If the spouse with dementia answered the questions "correctly", I had intended to send a letter to their physician as Step 3, informing him or her of his or her patient's interest in participating and ask if there were any concerns. As it turned out, that was not necessary as all spouses were referred to me by the same neurologist who had made the original diagnoses of Alzheimer's disease and believed the patients he referred to be appropriate for the study.

Informed consent in writing was obtained by the spouses at the first home visit. I reviewed the consent form with each couple and answered any questions the couples had about the research. Couples interested in participating signed the consent form before the study began. A copy of the consent form was left with the couples for their records and references. The couples were informed that they were free to withdraw from the project at any time, and/or refrain from answering any questions they would prefer to omit, without consequence. After the study has been completed a summary of the results of the study will be mailed to the couples as all of them were interested in receiving the information, indicated by their check mark on the consent form. The procedures for preserving anonymity and confidentiality included coding on all recording forms as I knew the identities of the participants because face-to-face contact was required to collect information. The key to decode their identities, along with their data, was kept strictly confidential, stored in a locked cabinet in my office. Any publications, presentations and reports will not have any identifying information. After the research is completed and the thesis accepted by the thesis committee the tapes of interviews will be destroyed.

Risks and benefits

A benefit of the study was that each couple had the opportunity to reminisce about the journey of their marriage. The recounting of their marital history, I believe, was helpful as it allowed couples to reflect on the happy experiences and their accomplishments in the life they have shared together. On the other hand, a risk of this study was that couples reflected on unhappy and difficult times. Although research suggests that older married couples are generally satisfied with their marriages, some potentially destructive conflicts between one couple did emerge. I had a list of resources,

such as referral for counselling, available for that purpose. However, I never needed to use it.

Once consent was obtained, I had the couples fill out the demographic information and administered the quantitative scales. At this visit, I also wanted to establish rapport and a trusting relationship between me, the researcher, and the couple, as participants. Demographic information were collected that included, age, educational attainment, employment history, religious participation, household composition, and the health status of both the spouses. Three scales were administered at that time to each spouse. The data from the scales was used to add other forms of data for the purpose of triangulation. One other purpose for the use of the scales was to sensitize respondents to questions related to their marriage. In this way the scales acted as a screen to ensure the couple were comfortable talking about their marriage and a flag to alert me, the researcher, of couples not appropriate.

Instrumentation and psychometric properties

The Dyadic Adjustment Rating Scale (Spanier & Thompson, 1976)

The Dyadic Adjustment Scale is a 32-item Likert scale that has four subscales that measure the marital relationship in the following areas: marital agreement or consensus on household tasks; tension; companionship; affection and sexuality; and commitment (see Appendix E). The Dyadic Adjustment Scale is a widely used scale with established criterion-related validity ($p<.001$) and construct validity (alpha.96). Spanier and Thompson (1982), using a confirmatory factor analysis, found that the four subscale factors accounted for 94% of the co-variance among the items and that three subscales were quite well replicated.

Scores

Consensus on household tasks – the maximum consensus score on this scale is 78; the lowest is 13.

Tension within the marital relationship – the maximum score, representing lowest tension, is 30; a score of 5 indicates very high tension.

Companionship within the marital relationship - scores can range from 6-36, with 36 representing very high companionship.

Affection and sexuality within the relationship – the maximum score representing high affection is 30; a score of 6 indicate no affection.

Commitment and the marital relationship – past marital happiness ranges from perfect to extremely unhappy. The middle point, *happy,* represents the amount of happiness in most relationships.

The Role Orientation Subscale (ROR) (Snyder, 1989)

The Role Orientation Subscale measures attitudes regarding conventional and unconventional gender role preferences (Snyder, 1989). The ROR consists of 25 items with "yes and no" answers, and, the higher the score, the more traditional the marital partner's perception of gender role. The ROR will serve as a supplementary scale to the Dyadic Adjustment Scale in order to sensitize the respondents to talking about marital sex roles.

The Role Orientation Subscale (ROR) is one of the eleven non-overlapping subscales of the Marital Satisfactory Inventory (see Appendix F). The Chronbach's alpha coefficient of internal consistency and the test-retest reliability coefficient for ROR are .89 and .89 respectively. The subscale has a low correlation with the rest of the Marital

Satisfactory Inventory scale in a factor analysis, signifying its independence from other subscales (Snyder, 1989, cited in Cheung, 1999, p. 367).

Cultural or symbolic notions of gender tell us what it means to be a man versus woman in a specific socio-cultural context (Osmond & Thorne, 1993). For example, "a 'real man' may be defined as tough, emotionally inexpressive, sexually aggressive, the breadwinner and the disciplinarian of his children, and a 'real woman' may be defined as the opposite" (Osmond & Thorne, 1993, p. 606). Understanding the gender role perceptions in the marital relationship will highlight the 'equality' or 'tradition' of roles. Kulik (2002) examined marital equality and the quality of long-term marriage in later life. Equality in the performance of in-home roles correlated positively with burn-out among husbands. Equality in power relationships correlated positively with marital satisfaction among wives.

Commitment to the Spouse (Swensen & Trahaug, 1985)

Commitment to the Spouse consists of two questions based on Swensen and Thauhag's (1985) work (Appendix G): (1) Why did you marry your spouse? and (2) Why have you stayed married to your spouse? The authors found significantly fewer marital problems in long-term marriages when the partners' commitment is based on valuing the spouse as a unique person versus valuing marriage as an institution. For example, the answer "*It's natural to get (stay) married*" would indicate a spouse's commitment to marriage as an institution, while the answer "*There is (was) no one like him (or her)*" would indicate that the spouse is perceived as a uniquely valued person (Wright, 1993, pp. 98-99).

The spouses' answers are rated on a continuum of "1" through "5", with "4" and "5" indicating that the spouse was valued as an unique person, "1" and "2" that marriage

was valued as an institution; "3" is given to answers that are equally strong in both sentiments. These two questions were used to assess whether there has been a change in commitment to the spouse as a uniquely valued person over the course of the couple's marriage. "*Why did you marry*?" is considered to be the beginning of a couple's relationship and "*Why have you stayed married*?" is considered to be the present. Swenson and Trahaug (1985) found in their research that there was reciprocity in commitment to each other, as well as a decline in commitment to each other as persons; but for those who have a commitment to each other as persons, there are significantly fewer marriage problems. Also, for those who increase their commitment to each other as persons, there are not only fewer marriage problems, but also an increase in the love expressed to each other (p. 944). The authors report inter-judge reliability for the answers to the questions measuring .83, and the answers differentiated between happily married couples (who valued their spouses as unique persons) and unhappy couples (who valued marriage as an institution).

The adopted scale, the DAS, ROR, and Commitment to the spouse, were used as triangulation (Denzin & Lincoln, 1994) which contributes to different aspects of understanding the phenomenon of commitment to the marriage relationship and the dementia experience. Quantitative data analysis principles and methods, such as frequencies, averages, etc., were applied to analysis, but no statistical analysis was applied as the sample was too small and two couples filled out the questionnaires together. In-depth interviewing, using a narrative approach, was the major tool for asking couples to recollect their memories and recount their marital experiences and the impact dementia had on their lives as a couple.

The second home visit

I made second and third home visits to the Campbells only. With the rest of the couples I interviewed, I combined the two visits into one. I found that the second couple I visited could comfortably answer the research questions with the one visit. I also did not want to start the second visit with the focus on dementia. Having the conversation flow as the discussion of marriage progressed seemed more natural to me. The stop and start of the Campbells' two home visits was somewhat disconcerting, and I think we lost momentum in the second interview. We had to start with a review of the first visit and got off topic somewhat. I was much happier with the combined second and third visit. As well, some of the later participants were not as articulate as the Campbells, and the two interviews would have been shorter and less informative.

The focus of the in-depth interview was with the spousal couple in an effort to see how they mutually constructed their story. In in-depth interviewing, social interaction between the interviewer and interviewees is part of the interview itself and generates both tone and content for data collected (Gubrium & Sankar, 1994). I used good interviewer skills by developing a trusting and mutual respectful relationship with the couple. I also spoke and acted in a non-threatening way. I took on a neutral role but was compassionate and empathetic towards the spouses. Morse and Field (1995) suggest that in "telling their stories," participants will relive their experiences including emotional responses. If the topic is stressful the researcher needs to be prepared for sadness and anger. "Narratives bring it all back," even though a participant will not tell you anything they do not want you to know, but it is important for them to control the pace (p. 92). I did experience extreme sadness and pain along with the Martins as they relived the tragic accidental death of their seven year old daughter. We sat in silence for a period of time after the

recounting of the experience, crying together. They told me they had not talked about in a long time.

A semi-structured interview guide was used to obtain couples narrative stories about their 'relationship-biography' and covered questions about expectations and enactment of commitment to the marriage relationship retrospectively and prospectively and the experience of dementia. Although the questions were prepared in a logical, chronological order, and each question addressed one aspect of the topic I found that couples in responding to one question answered others as well. The interview guide was pre-tested on the Campbells. For the most part I did follow the prepared order of the main themes chronologically with the Campbells, but did not always stick to the structure of the probes. I did not want to interrupt but sometimes needed to as Mrs. Campbell the spouse with dementia went too far off topic and began to repeat herself. With the rest of the couples, I used a much less structured approach and asked them to provide examples. In this way they would answer some of the questions without me asking. It felt as if we were having a conversation using this approach, and it allowed me and, I believe, the couples as well, to be more spontaneous. Suggested additional follow up questions were included for example, "*In what way…*?" or "*Please explain….*," or "*Can you tell me a time when that happened….*?"

The following is the interview guide and probes (o) I used to elicit couples' stories:

(1) Tell me about when you met and married –"your wedding story"

- o What kind of commitment did you make to each other?
- o What does commitment mean to you then and now?
- o What is it like to be a couple?

(2) Tell me about the history and satisfaction of your marriage relationship.

- What about the early years, the middle years, and now?
- What about the strengths and difficulties of your marriage?

(3) Who received the news of the diagnosis, and how did it happen?

- What does this diagnosis mean to your marriage relationship?

(4) Tell me about specific times when you cared for each other when you were ill.

- How will you care for each other now that one of you has dementia?

(5) What are your roles and responsibilities in the marriage?

- Past?
- Current?

(6) Tell me about what help you think you may need in the future.

- A year from now, 5 years from now
- As a care provider
- As a person with dementia
- Who do you think could provide support?

Narrative and narrative analysis

> *"Telling and listening takes place within the context of a relationship between two persons or person and text."* (Cohler, 1994, p. 170).

A narrative or story in its broadest sense is anything told or recounted; more narrowly, something told and recounted in the form of a causally-linked set of events; account; tale; the telling of a happening or connected series of happenings, whether true of fictitious (Denning, 2000). Narratives are important units of discourse for research because they allow for the construction and expression of meaning (Riessman, 1994). Narrative comes from the Latin word *gnarus* meaning knowledge, that is, a telling history (McCabe & Patterson, 1991). Narrative is commonly understood as a story that has a

plot, a beginning, middle, and an end (Sherman & Reid, 1994, p. 7). Labov (1972) defined narrative as one method of recapitulating the past experience by matching a verbal sequence of clauses to the sequence of events which (it is inferred) actually occurred (cited in Franzosi, 1998 p. 519). Franzosi claims that definition came from common roots by the Russian formalists, Propp (1968) and Tomashevske (1965), who introduced the distinction between "story versus plot" in narrative (*fibula vs sjuňet*). These formalists built on Aristotle's idea of plot-structure of *mythos* – in the master's own words. Tomashevske wrote that "plot is distinct from story. Both include the same events, but in the plot the events *are arranged* and connected according to the orderly sequence in which they are presented in the work," He continues in a note, "in brief the story is 'the 'action itself, ...[the plot is] how the reader learns of action''(Franzosi, 1998, p. 519).

According to McCabe and Patterson (1991), "we are the stories we tell" (p. x). Story telling is what we do with our research materials and what informants do with us (Riessman, 1993). Through narrative people translate knowing into telling (Cheung, 1999), "Narrative is a vital human activity, a mode through which people explore meaning and express their understanding of events and experiences" (Cheung, 1999 p. 55). Narrative provides a root metaphor for understanding a framework of the construction of the past in terms of events (Cheung, 1999). Telling stories about past events is one of the first forms of discourse we learn as children (Nelson, 1989) and used throughout the life course by people of all social and cultural backgrounds. Stories are narratives with plots which "knit events together", allowing us to understand the deeper significance of the event in the light of others (Gabriel, 2004, p. 170). Consequently, Gabriel suggests, stories purport to relate the facts that happened and to discover in these

facts a plot or 'meaning'. Facts then do not "just happen" but they happen in accordance with a plot (p. 170). They represent poetic elaborations aimed at articulating *facts as experience,* not *facts as information* (p.170). Narrative is considered a primary form of expression where people present their life events in a coherent and meaningful theme (Cheung, 1999).

Narrative analysis, a systematic way of listening to interviews and re-presenting qualitative data, is but one way of bringing greater rigor to qualitative research (Poindexter, 2002). It highlights the interviewer's co-construction of the data and facilitates detailed transcripts for analysis. Narrative analysis takes as its object of investigation the story itself. According to Riessman (1993) the purpose of narrative analysis is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives. The informant's story is examined and analyzed to see how it is put together, the linguistic and cultural resources it draws on, and how it persuades a listener of its authenticity. For example, the researcher may say, "*Is this one story with related subplots or a series of different stories*?" (Mishner, 1986, p. 73). Analysis in narrative studies open up the form of telling about experiences, and not simply the content to which language refers. We ask, "*Why was the story told in that way*?" (Riessman, 1993, p. 2).

Nature and the world do not tell stories, Riessman (1993) argues, individuals do. An interpretation is inevitable as narratives are *representations*. There is no hard distinction in postpositivist research between fact and interpretation (Stivers, 1993). Human agency and imagination determine what gets included and excluded in narrativization, how events are plotted, and what they are supposed to mean. "Individuals construct their past events and actions in personal narrative to claim identities and

construct lives" (Stivers, 1993, p. 2). People by nature lead storied lives and tell stories of their lives. Narrative researchers describe such lives, collect and tell stories of them, and write narratives of experience (Oliver, 2004 p. 245).

Although individuals construct past events and actions in personal narrative, the qualitative researcher is the primary instrument for data collection and analysis. The research 'co-constructs' the stories with the participants through a process of trying to make sense of the data by contrasting, comparing, replicating, cataloguing and classifying the object of the study (Creswell, 1994). In other words, the researcher embraces a relational understanding of the roles and interactions of the researcher and researched (Pinnegar & Daynes, 2007).

Mishler (1986) concurs with the notion of the importance of the interviewer and the interview context. He expands on this by stating that the interviewer's presence and form of involvement, that is, how she or he listens, attends, encourages, interrupts, digresses, initiates topics, and terminates responses, is integral to a respondent's account. It is in this sense that the "story" is a joint production (p.82). This fits with constructionism as interviewers and interviewees are always engaged in constructing meaning. How research is meaningfully constructed becomes the researcher's topic (Silverman 2004).

Walker and Dickson (2004) explored illness-related narratives constructed through narrative analysis and established the notion that couples' illness-related stories were indicative of the couples' relationships, cultures, and identities. In an examination of narrative analysis of family caregiving, Ayres (2000) found caregivers told four types of stories: stories of ideal lives, stories of ordinary lives, stories of compromised lives, and ambiguous stories (p. 359). Corbin and Strauss described biographical work, a

process of meaning-making, as a component of living with chronic illness (cited in Nolan, Grant, & Keady, 1996, p. 137). Biographical work demonstrates the integration of a situation such as chronic illness within the larger context, the past, present and future as caregivers try to make sense of the changes the illness creates in their lives (Ayres, 2000).

Narrative analysis can help broaden our lens and provide a deeper level of understanding into the lives of couples in marriage experiencing dementia. The narrative analysis of the biographies of married couples facing dementia focuses on the larger context of past, present, and future, and is therefore an appropriate method for understanding the impact of commitment of the marriage relationship on the dementia experience.

There is a great deal of diversity in narrative research, and no standard approach to conducting narrative analysis (Fraser, 2004). Whether the priority of analysis is *syntax*, meaning how people construct their stories, *semantics*, the linguistic analysis of meaning, or the *interactional* context, depends on the intent of the researcher. In my study, I chose Mishler's (1986) interactional narrative interviewing and Riessman's (1993) narrative analysis schema to conduct my narrative analysis. I also used the method of Agar and Hobbs (1982) to analyse themes that emerged as a result of meaning-making processes that the respondents experienced in their marriages in order to understand the impact of commitment to the marriage relationship on the dementia experience. The narrative analysis schema that I used focuses on three analytically distinct but interdependent functions borrowed from Halliday's systematic theory of grammar (Mishler, 1986, pp. 76-77): (1) the textual function referring to how parts of the text are internally connected

through various syntactic (structure) and semantic (language) devices;[7] (2) the ideational or referential function, referring to the meaning of what is said (content); and (3) the interpersonal function referring to the role relationships between speakers that are realized in the talk. I believe the above techniques are complementary methods that together provide a more complete understanding of how the personal experiences of couples situated in their cultural context, contribute to text interpretation. The specifications for the five stage research process used in the analysis of the study are based on Riessman's (1993, p. 10) level of representations in the research process (Figure 4). The following summarizes the inductive research process and my essential steps in narrative analysis based on Reissman's levels of representation.

Step 5
Reading experiences by
presentation of results to the readers

Step 4
Analyzing experiences and theoretical abstraction

Step 3
Transcribing narrative experiences
and interpreting meaning

Step 2
Telling about experience through
research-respondent interaction
during in-depth interviews

Step 1
Attending to experiences

Primary experiences of long-term
married couples

Figure 4: The inductive research process

[7] Semiotics, or the science of *signs*, provides a set of assumptions and concepts that permit systematic analysis of symbolic systems. A *sign* is something that represents or stands for something else in the mind of someone. A sign is composed of an *expression* such as a word, sound, symbol, and a content, or something that is seen as completing the meaning of the expression (Manning & Cullum-Swan, 1994, p. 466).

Step one: Attending to experiences: the researcher-responder interface

Mishler (1986) emphasized the interview relationship as an interaction between the researcher-listener and respondent-narrator. Emphasis is placed on the importance of the researcher or interviewer as co-participant in the creation of the narrative text (Chambon, 1995; Riessman, 1993). Questions and answers become a circular process where questions have no predetermined meaning and serve to elicit a response (Mishler, 1991). The co-creation of narrative is jointly produced through the interaction[8] between the interviewer and respondents, situated in a particular time and context (Cheung, 1999).

By attending, I made certain phenomena meaningful to the couples. Each couple was interviewed in their home. I told the couples that the research interview was about their reflecting, remembering, and recollecting on their marriage relationship, from the time they met and married, to the present. The couples were told they would present their experience and I would interpret it. In this way, I suggested, we were a research team. What was meaningful for me to understand, I told them, was how they interpreted commitment in marriage and how commitment impacted on their experience of dementia. As a co-creator of the research, I provided couples with a background into my experiences, skill, and knowledge working with couples in the area of dementia.

[8] In the classic interactionist model of documentary analysis, a solitary internalized reflexivity takes place. An embodied person (1) (with a name, personal identity, and location in time and space) performs an action, "writing" (2). This action, reflecting a "self," including both an "I" and a "me," is reflected upon the self writing and reads the product as an activity reflecting upon the role of "writer." Writing represents an aspect of a writer's self. The writer's self is displayed in the text (4). The products of self-conscious writing activity, "texts" (diaries, stories, biographies, research etc.) and read (5). These "readings" are re-representations of the writer's documentary presentation of self (Manning & Cullum-Swan, 1994, p. 468)

Step two: Telling about experiences through researcher-respondent interaction during in-depth interviews

My techniques for joint interviewing of the couples

"*Interviewing is rather like a marriage: everyone knows what it is, an awful lot of people do it, and yet behind each closed front door there is a world of secrets.*" (Oakey, 1981 as cited in Denzin and Lincoln, 1994 p. 374)

In the context of this study, joint interviewing meant that I interviewed the spousal couple together to collect information on how they perceived commitment to their marriage relationship. Joint interviewing is commonly used in the context of inquiries involving people in marital relationships (Arksey, 1996). I did encounter some problems, for example, when one respondent would dominate the other and when one spouse provoked friction and disagreement between the couple (Arksey, 1996). On the positive side, I found joint interviewing helped me establish rapport with the couple in their relationship and signaled an atmosphere of equality where both voices were heard. The spouse with dementia gained confidence and was less fearful of expressing him or herself. Joint interviewing revealed a different kind of knowledge, a "joint production of meaning" that could not have been reported by each spouse. It was a helpful process for spouses with dementia in that they felt safe in their own home with the support of their spouse and both filled in each other's gaps and memory lapses (Arksey, 1996). More specifically joint interviews added to insight into interactions and the nature of relationships between the study couples through observation of non-verbal modes of communication (Arksey, 1996). This technique enables the voices of those with dementia, who might otherwise be silent, to be heard, for example, when a spouse acted as a 'prompt' or 'translator' on behalf of her/his partner with dementia.

Another reality that Arksey suggests to keep in mind is that interview data from joint interviews is different from one-to-one conversations because, rather than an individual construction of events, a jointly constructed picture of events is created. This sort of 'collaboration' supports the idea that joint interviews produce more consensual data and couples may tend to report socially acceptable behaviour. I found this to be true. Most couples reported always doing things together as partners; therefore a joint interview was appropriate for this study.

The methods I used to engage couples in the research process were based on my experience working with couples, first as a home care nurse; then as a social worker when I interviewed spouses prior to a move to personal care; and then for attendance at a dementia specific day program; for research purposes; and finally at a memory clinic for diagnosis of Alzheimer dementia. The use of conversation prior to the interview, and my experience of observing and listening during the conversation acted as a springboard to an approach that helped me with this research project. I found the following approaches helped me. Throughout all of the interviews, the most important thing for me to do was establish a trusting relationship with the person experiencing dementia. If I was not able to do that, the person would "shut down," and probably not agree to be a research participant. My experience suggested that the caregiver spouse would "take the side of their husband/wife." I needed both spouses to feel engaged and comfortable in my presence. I acted as a guest in their home, and, as a guest, told them I felt privileged to be with them. My experience suggested that engaging in a trusting relationship would positively impact on how the couple told their narrative story about commitment in marriage and the dementia experience. As Goffman pointed out in his book, *Interactional*

Ritual, individuals must be in a state of readiness for face-to-face encounters or they can become alienated from a conversational encounter.

> *As a main focus of attention talk is unique, however, for talk creates for the participant a world and reality that has other participants in it. Joint spontaneous involvement is a* ***unio mystico****, a socialized trance. We must also see that a conversation has a life of its own and makes demands on its own behalf. It is a little social system with its own boundary-maintaining tendencies; it is a little patch of commitment and loyalty with its own heroes and its own villains* (Goffman, 1969, p. 113-114).

Deciding how to present oneself in an interview is important. As Denzin and Lincoln (1995) remind us, our presentational selves are "cast" during that time and can have a profound impression on respondents, influencing the success or lack of success of the study (p. 376). During my initial visit with the couples, I used a friendly, informal, non-institutional introduction. The home environment was used as a source of topics to begin the conversation and establish common ground. Three approaches to establishing rapport and a "state-of-readiness" proved successful: (1) establishing a common ground; (2) trustworthiness of the project; (3) setting the context properly. Theoretical support for these approaches was based on a strengths perspective and conflict resolution skills.

First, establishing a common ground was accomplished through the skills of observation and experience. I phoned each couple the day of the interview to make sure they were expecting me. I introduced myself and reminded them that I was visiting as part of a research project on marriage commitment, and that I was affiliated with the Memory Clinic. The home environment provided a context for an environmental assessment. I scanned the environment to get a sense of what was going on in the home. Was the environment safe, clean, homey? I was interested in observing how couples expressed their relationship in the context of their home. Most couples had family

pictures of children, grandchildren, and pets within viewing distance, and enjoyed sharing information about their family with me. I would notice they enjoyed talking about their home and how they "put it all together" over the years. I spent approximately 20 minutes during the initial visit getting to know the couple in their environment, talking about *them* and their opinions and beliefs in whatever came up in the conversation, all the while observing their style of interaction as a couple.

Second, the trustworthiness of the project was sanctioned by the referral from the neurologist and by the University of Manitoba. The couples believed they were part of a vital and important project, that they did not have to say anything they did not want to, that what was important were their viewpoints, that there were no right or wrong answers, and that the research had the potential to help others in similar situations to theirs.

Lastly, setting the context properly meant establishing boundaries for the interview. Each spouse sat opposite each other at the kitchen or dining room table. The spouses took turns talking and telling me their stories the way they wished. The couples understood when that when I would write it up it would become "our story", as *my* interpretation will impact on *their* story. I told the couple what kinds of questions I would be asking at the end of the first home visit to give them time to think about their responses. I reviewed the type of questions I would be asking prior to turning on the tape recorder. It was important for me to keep the interviews on track in a diplomatic way. This meant at times I took on many different roles such as negotiator, arbitrator, peacemaker, and investigator, as the couples co-constructed the events of their long-term marriages, their commitment to marriage and each other, and the experience of dementia.

I concur with Fraser (2004) who offers practical 'how to' suggestions on conducting narrative interviewing:

- Prepare for the interviews by studying the socio-historical contexts of participants' lives;
- Respond to different communication styles;
- Avoid 'mining' interviewees for information or 'cross-examining' them;
- Demonstrate sensitivity to the time frames as well as our own;
- Facilitate a climate of trust;
- Allow participants to ask questions of their own, as well as how we might respond to any questions they raise;
- Reveal our own investment in the research;
- Share some of the interpretations we make; and,
- Appreciate the politics involved with making knowledge (p. 184).

There were two significant difficulties experienced in interviewing couples when one spouse has dementia. First, the person with dementia was easily silenced when the contents of significant life events were forgotten or mixed up. For example, Mr. Gladstone talked about not needing a second car because he took the bus to work. His wife reminded him that ***she*** bought a little red Honda (adorned with a big red bow), that the dealer delivered Christmas morning. "*Why did we get a second car? Please*? he questioned his wife. After she told him, he responded, "*Yeah. But with my memory, I can't even remember it.*" Second, the person experiencing dementia had difficulty evaluating the outcome of life events. For example, when I asked Mrs. Martin if she felt some deterioration taking place in her memory as her husband suggested, she said, "*I feel it. I don't know exactly how they look at it. I find that I always have to, I have to come to a point so that I can verbalize properly. Just like this, you know, it's gone, you know, and...*" Even though the spouse with dementia fragmented their personal stories, or lost memory for details, the other spouse most often compensated by filling in the story gaps, reviving the memory, thus saving face for their partner.

Fraser (2004) expands on 'attending to the experience' by suggesting researchers hear the stories and experience each other's emotions. Clues to the genres of the stories unfold by reflecting on the body language used and the feelings described. By keeping a journal about time, place, and emotional climate, and answering such questions as: "*What sense do you get from each interview? How are emotions experienced during and after the interview?*" I was able to describe the feelings that emerged from the home visits as suggested by Fraser (2004 p. 87). For instance, my journal notes from the second home visit to the Gladstones reported emotional tension between the couple.

> *When I arrived, Mrs. Gladstone anxiously whispered to me that her husband was put on a sedative after an angry outburst regarding the purchase of a new TV. The 20 year old TV was no longer working and their son is purchasing a new TV. Her husband wanted the old one fixed. The argument lasted an hour. Mrs. Gladstone was not able to reason with her husband. He is calmer now, she reported, things are better. Mrs. G. made coffee. We sat at the dining room table, chatting for 15 minutes about the Alzheimer Support Group she attended, her home and daughter while Mr. G. was finishing breakfast.* (Journal notes, September 22, 2006)

The interview started and ended with Mrs. Gladstone challenging her husband's memory. Their relationship "sparked" during the interview. Mr. Gladstone seemed to take the opposite position on meaning of events and hold firm. Mrs. Gladstone had had to put up with a lot of disappointments in her marriage and she resented that.

In telling about the events of their married lives the couples re-present them enacting the action in conversation, taking the form of a narrative about what happened. They describe the setting, characters, unfolding plot, and stitch the story together in such a way as is meaningful for them. I in turn asked questions, for expansion of a response. By talking and listening we produced the narrative together (Riessman, 1993).

In their telling of their experiences, there was an inevitable gap between the experience as couples lived it and any communication about it. According to Canfield (2004), humans possess a symbolizing, sensemaking ability. They learn to manage themselves in a complex social world, trying to act in accordance with the perceived expectation of the situation. In face-to-face situations, humans talk to others using both body and words. The body "speaks". What it is saying is a matter of interpretation (p. 1). Couples telling about their experiences created "selves," how they wanted to be known by me in the context of their story, their culture, and gender. Constructing a coherent story about one's life is a crucial factor in the formation and establishment of one's identity (Mishler, 1991). For instance, my journal notes for the first home visit with the Campbells provide an example of how this couple wanted to be known by me, the researcher, in their socio-cultural context.

The couple talked at length about their 'high society wedding', planned for them, with about 300 distinguished guests. Mr. Campbell got out a book on "who's who" in Canada and pointed out wedding guests by name from the book. The couple talked about their privileged life growing up on and around the grounds of a famous Quebec university. The couple claimed a stable successful family history of marriage with the proper attitudes instilled in them as children, the responsibility of children and society. Their parents acted as role models. They, in turn, have four successful well educated professional children and now their children excel just as their parents and grandparents to maintain the family place in academic and social excellence. (Journal notes from March 22, 2006).

Mr. Campbell presented himself to me as a competent morally obligated person with a strong Victorian belief in family tradition. It was the family tradition and responsibility to care for one another during illness, "to do your duty."

Open-ended questions provide a context for participants to attend to and tell about important events in marriage. Mishler (1986) suggests it is better to open up topics which allow respondents to construct answers, in collaboration with listeners.

To facilitate recall, I asked the married couples the following types of questions to help elicit stories.

- Tell me about how you met and married, your "wedding story".
- What kind of commitment did you make to each other?
- What is it like to be a couple?
- Tell me about times you cared for each other when you were ill.
- Who received the news of the diagnosis of dementia, and how did it happen?
- What does the diagnosis of dementia mean to your marriage relationship?

Joint interviewing offered me insights into the interactions and the nature of (power) relationships between the couples through observation of non-verbal modes of communication. I believe joint interviewing provided a safe secure environment for the spouse with dementia and thus empowered them to tell his/her story "along side" of their partner's. The couple's different perceptions on the same topic would likely have been lost if I had just interviewed the carer or if I interviewed the husband and wife separately. So often in dementia research perceptions of the person with dementia are inferred from the data given by the carer. It was through their "joint production of meaning" that I was better able to fit their story pieces together into a coherent whole. I found as Arksey (1996) suggested, that a carer would often act as a prompt or translator on behalf of a person with dementia.

The nature of joint interview data is qualitatively different from obtaining data during one-to-one conversations (Arksey, 1996). This partly reflects the fact that the latter is an individual reconstruction of events, opinions, and the like, whereas the former consists of a jointly constructed picture. I did find couples reporting a unified image of reality. More consensual data was reported, and overt conflict during the course of the interview was the exception rather than the rule. The couples tried to present themselves

in a favourable light consistent with the likelihood that they were presenting their "public" accounts of socially acceptable behavior (Arksey, 1996). It has been suggested claims Arksey (1996), individuals use the joint interview occasion to legitimize or justify their actions, or, alternatively, to normalize their situation. Consistent with Arksey's findings on doing joint interviewing, setting up the joint interview was a long drawn out process. Both partners needed to agree. It took nine months to recruit the six couples interviewed for my research. Three additional couples were referred by the Memory Clinic, but the couples refused for the following reason: When I telephoned the first spouse, she replied, "*I don't want to put my husband through that. He has been through too much as it is.*" The second, a wife as well, told me her husband did not hear well enough to be interviewed. The third, a wife, claimed she was just too stressed with caring for her husband and his behaviour had become worse of late.

Step three: Transcribing narrative experiences and interpreting meaning

The analysis of data started with a review of the transcripts. I listened to the audiotapes and made corrections to the text and documented additional nonverbal information (such as changes in verbal tone and emotional expressions). Names and other identifying features were changed at that time.

The narrative analysis method I adopted focused on interpreting commitment to marriage meanings and dementia meanings embedded in couples' social context, by outlining themes of the interview texts of couples' marital experiences in the form of different narrative genres. In order to ensure that I, as a researcher, interpreted couples' lives as ethically and respectfully as possible, I chose to represent text by focusing on each respondent's own expressions and perceptions as much as possible (Poindexter, 2002). Individuals relate experiences using a variety of narrative genes (Reissman, 1993).

I identified five narrative genres suggested by Reissman (1990, and cited in Cheung, 1999, pp. 64-71) in the interview texts – stories, views, metaphors, non-lexical utterances, and habitual narratives.

Stories

Stories are abstract constructs that the reader has to derive from the concrete text (Herman & Varvaeck, 2001). The story metaphor emphasizes that we create order, construct texts (transcripts of interviews) in particular contexts (Reissman, 1993). Unlike some traditional approaches to qualitative analysis that fracture text by taking bits and pieces or snippets of a response edited out of context, narrative analysis emphasizes the story as a whole (Reissman, 1993). The focus is on the sequential and structural features of the story.

Storytelling as a response to interview questions differed among couples. The wives caring for husbands told their stories in the most natural way. Men caring for their wives told more stories in metaphors and views and were often very articulate in their narratives about their marital experiences. Both husband and wife could unite in the joint interviews to tell their stories of commitment to the marriage and the dementia experience. They took turns filling in gaps and reinforcing the partnership aspect of the marriage. Those participants with dementia were certainly not silenced by the interview or topic. They often presented their views, particularly on how it felt to have losses to their memory and their dependence on their spouses.

I used Labov's (1972, 1982) structural approach to understand how speech events or unite of language are organized and connected to each other through the relation of temporal order (Halliday's textual function). Labov defines a minimal narrative as a sequence of two clauses which are temporally ordered; that is a change in their order

results in a change in temporal sequence. That means the clause cannot be moved to any other point without a change in its semantic meaning. Clauses are classified into one or the other of six categories of a fully formed narrative.

1. **Abstract**: refers to a brief summary of the substance of the narrative as viewed by the narrator; the point of the narrative; answers the question - what was this about?

2. **Orientation**: refers to the time, the place, the participants in the action, and their general behavior before or at the time of the first action; answers the questions - who, when, what, where?

3. **Complicating action**: refers to reducing the narrative to the skeleton outline of narrative clauses, and to outline the generating mechanisms that produce the narrative backbone; answers the question - then what happened?

4. **Evaluation**: refers to the contrast of what did occur and what did not but might have occured serves to evaluate narrative; answers the question - so what?

5. **Resolution**: answers the question - what finally happened?

6. **Coda**: returns the perspective to the present.

With these structures, a teller constructs a story from a primary experience and interprets the significance of events in clauses and embedded evaluation (Riessman, 1993). The simplest narrative consists of two events linked by a 'temporal juncture,' a shift in time. By this definition, the statement "first this happened and then that happened" constitutes the simplest form of a narrative (Nye, 1994, p. 219) and the researcher has a story. Labov defines narrative structure: this way "Plot is, in every sense of the word, the articulation of the skeleton of the narrative, and plot can be defined as the dynamic, sequential element in narrative literature" (Mishler, 1982, p. 81). According to Labov (1972), evaluative devices are distributed throughout the narrative. In Figure 4 evaluation is seen as the focus of waves of evaluation that penetrate the narrative (p. 369).

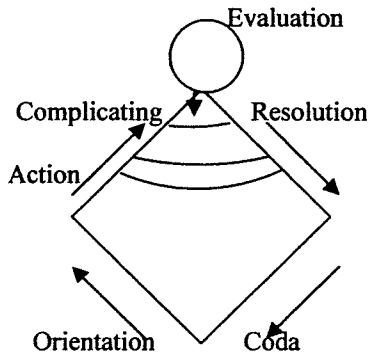

Figure 5: A complete narrative

A complete narrative begins with an orientation, proceeds to the complicating action, is suspended at the focus of evaluation before the resolution, concludes with the resolution, and returns the listener to the present time with the coda. The evaluation of the narrative forms the secondary structure which is concentrated in the evaluation section but may be found in various forms throughout the narrative (Labov, 1972, p. 369).

Drawing on Labov's structural approach recommended by Mishler (1982) and Reissman (1993), I reduced the full account shown in the couples' transcripts to a "core narrative" consisting of approximately 25% of the original text and then specified the constituents: Abstract, Orientation, Complicating Action and Resolution. I examined how word choice, structure, and clauses echoed one another. I examined how the sequence of action in one story builds on a prior one. The emphasis was on language – how people say what they do and what they are – and the narrative structures they employ to construct experiences by telling about them (Riessman, 1993, p. 40). Next I used the evaluative comments and arrived at an interpretation of the "point" of the story.

The relationship between the abstract and resolution gave me a sense of cohesion and closure. I could conclude that what lies between the beginning and ending points is a connected narrative (Mishler 1982, pp. 103-104).

Views

In most cases, the respondents' views represented their evaluation of the lived experience, of commitment to marriage and the dementia experience, and the fourth element in Labov's structural analysis of story. For example, here is an exchange with a couple as they talk about their marriage relationship over the years and respond to my question (J).

J: So if you had to do it over again, would you?

Mr. P: Sure, I would.

J: Would you?

Mr. P: You would change things. You would do things a little different because...

Mrs. P: Because we've gone there already.

J: Uh hmm.

Mr. P: When you go down the wrong road and you have to make a correction, you know, you change things, right? And obviously we would change things and I think everybody would. I don't think anybody would go the same path. They might do it over again, but on a different path.

Mr. P. refers to the fact that he, like most married couples, would change things about their marriages if they had to do it over again. This was a general view, but he referred back to his own marriage with his wife's response and he started to recount his story of how he managed change in the marriage.

Mrs. P: In a different path. There's just certain things you pick out of there. We tried that, we're not going that way, that route.

Mr. P: And over a span of time that we've lived together, you know how to deal with certain issues, you know. I mean at this stage, I mean, with her, if there's something coming up, I know when to leave it alone and I know when to talk about it, you know, because if it's a big event, she gets riled up over it, so I avoid those things.

Mrs. P: He says that's where we are going and that's the way it goes.

These views of couples when one spouse has dementia are typical. The spouse with dementia is often no longer able or willing to make day-to-day decisions and it is left to the other spouse to take charge, leaving their partner with no option. The result is the spouse with dementia feels frustrated and angry but knows she/he can't survive at home without the support of the spouse.

Metaphors

Metaphors are used to describe experience, representing the gist of the story similar to the poetic narrative. In Poetics, Aristotle said, a narrative has a beginning, a middle, and end, and according to Riessman (1993), this type of sequence is necessary, if not sufficient for narrative. For example, one spouse told a metaphor to explain what life commitment meant to his marriage relationship.

Mr. M: Quite a bit later in life, I realized that there was a sort of very childish type of saying. It was, you know, somebody saw as 'Footprints in the Sand' and he says, there's only one single footprint in the sand and the other person turned and said, Yes, that's the time when I carried you! Okay? And that sort of made a good impression on us and he said, This will happen in life, when the time will come that one is not capable or able to commit to do the 100% commitment. It may be 45% or 50 %. Then the other person has to be prepared to take 150% and when it comes to the point where he has to take, or she has to take 200% for a while and walk through the sand, that's a sign that somebody is carrying the other person, so that's a commitment. And so that's where it is. That's where we are.

J: Do you agree with that? (I asked the wife)

Mrs. M: Yeah, uh hmm.

Other types of genres

Referential narratives – This genre occurs when the narrator derives views from comparing his/her situation to stories of others. I did not encounter the genre of referential narrative in the couples' narratives.

Non-lexical utterance – This genre occurs with expressions like "hmmhmm" "uh-huh" "eh", and is useful in understanding respondents' hesitation and emotional involvement in their narratives, as well as locating shifts in narration and considered utterances that supplement missing parts of the story. I did not encounter many non-lexical utterances perhaps because when there was a pause in the conversation, the other spouse would jump in with a comment. The most common utterance was laughing.

Habitual narrative – This genre occurs when events happen over and over and there is no peak in the action. One spouse with dementia repeatedly told the same story throughout the interview with no peak in action. Her repetition was the fact that she could use both left and right hand effectively. This made it easier for her to write down messages and hold the phone at the same time, thus helping her with her memory problems and taking messages for her husband.

Locating themes

Themes and subplots of stories are embedded in narrative (Misher, 1986), but the centerpiece of the narrative analysis is the plot (Oliver, 1998). In the analysis of couple's narratives, I had the task of examining the various events, happenings, and actions of the married couple's experiences with dementia and then weaving those experiences into a

thematic whole. It became important to identify the interrelationships of different subplots and themes to the general plot of the narrative. The analysis of the coherence of themes in narrative is an important means of developing trustworthiness of interpreting the meaning of the respondents' lived experiences encoded in their socio-cultural contexts. Agar and Hobbs (1982) propose three kinds of coherence in a narrative text as restated by Riessman (1993) and Mishler (1986).

1. **Global coherence:** represents a top-down view which reflects the narrator's beliefs and goals. Global coherence examines the relation between the respondents overall intent and local theme in narrative. All couples talked about marriage as a commitment for life, a partnership, for better or worse, and demonstrated this overall intent of global coherence throughout the narratives linking local themes such as 'doing things together.'

2. **Local coherence**: represents a bottom-up view which is generated from the core narrative of the narrator's story. It is the local theme of the episode in narrative.

3. **Themal coherence:** represents the recurrent themes that unify the text. The repeated occurrence of themes expresses the respondents' cultural assumptions and beliefs.

Narrative analysis consists of both hermeneutic (interpretation) and heuristic (a self-searching way of discovering) implications (Cheung, 1999). The heuristic expression of narrative analysis refers to the discovery of the nature and meaning of a

phenomenon through the researcher's inner awareness and inspiration during the process of his/her empirical investigation (Moustakas, 1990).

Content analysis

Data from the research was analyzed by topic, and each interview was segmented by these topics into categories. Codes were used to identify the content in the interview, and category labels which are descriptive names were used for each group of data. This process was called content analysis. Morse and Field (1995) suggest that 10 to 15 categories are necessary to begin the analysis; later many will be combined. Once the categories have ample data, I categorized these data into two or more subcategories. Thus a tree diagram develops with "Types of...." as the main category. When each category was reached, and no more new data are emerging, I wrote descriptive paragraphs about the categories and looked for relationships between the categories. The relationships were considered to be concurrent, antecedent, or consequential of an initial category (Morse & Field, 1995, p. 140). Examining transcripts for commonalities and differences that exist among and between participants may be done by comparing and contrasting the content, style, and tone of respective speakers (Fraser, 2004). While considering how stories align with the initial assumptions, Fraser (2004) suggests the narrative researcher may also want to note findings that are inconsistent, counter-intuitive, surprising and/or anomalous, confronting and/or unpopular. The following points highlight how I looked for commonalities and differences among participants:

- What are the emergent themes or patterns across the transcripts?
- How are common patterns or plots unveiled
- How are differences in themes, plots, characters, settings, and temporal ordering enunciated? If so, are they relevant to understanding the social role of stories?

- Are sensational, provocative or contentious stories deliberately fore-grounded, or conversely, avoided? If so, what are the implications?
- How are the experiences mediated by the material conditions in which narrators are living?
- Are stories that challenge the views on which the research is predicated given sufficient analytical attention? If not, how it this rationalized? (Fraser, 2004, p. 195).

Step four: Analyzing experiences and theoretical abstraction

Qualitative data, analyzed with close attention to experiences understood in terms of internal patterns and forms, are used to produce theoretical ideas about social processes and cultural forms beyond themselves (Silverman, 2005). "An investigator sits with pages of tape-recorded stories, snips away at the flow of talk to make it fit between the covers of a book, and tries to create a sense of dramatic tension. There are decisions about form, ordering, style, presentation and how the fragments of lives that have been given in interviews will be housed" (Riessman, 1993, p. 13). The stop-and-start style of oral stories of personal experience finally gets 'pasted together' into something different from the original storytellers' life story (Riessman, 1993).

I read the couples' full transcripts in conjunction with my field notes and journals, and the couples answers to the quantitative measures – DAD, ROR, and Commitment to the Spouse. I looked at the content and embedded meanings in the narratives and linked them up with themes. I then analyzed all data by topic, each couple's interview was segmented by topics into categories. Codes were used to identify the content in the interviews, and category labels which are descriptive names were used for each group of data. When each category was reached, and no more new data was emerging, I wrote descriptive paragraphs about the categories and looked for relationships among the categories.

I agree with Mishler (1986) in that my interpretation was contingent upon the knowledge I gained from existing literature and inferred from my professional knowledge as a clinical social worker working in the area of dementia care. Drawing on all that I know, I interpreted meaning and examined relationships between couples for meaning and their recounting of commitment to the marriage relationship on the dementia experience. I did not go back to the respondents for validation with tentative results and refine them in light of their reactions. I agree with Siverman (2005) that a problem arises if we attribute a privileged status to their account (p. 212). As it would have been a year later that I would have approached couples for respondent validation, I was concerned that recollection of interviews would be impacted by the progression of the disease process of the spouse with dementia and that could misrepresent my findings.

Step five: Reading experiences by presentation of results to readers

Every text is "plurivocal open to several readings and to several constructions" (Riessman, 1993, p. 14). As Riessman pointed out, a researcher's anticipated response to a piece of work shapes what is to be included and excluded. Even for the same reader, a work can provoke quite different meanings in different historical contexts. Texts stand on "moving ground" as there is no master narrative. Any finding – a depiction of a culture, psychological process, or social structure exists in historical time, between subjects in relations of power (p. 15).

Establishing trustworthiness in the research design of the present study

The basic issue related to trustworthiness is "how can an inquirer persuade his or her audience (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?" (Lincoln & Guba, 1985, p. 290). Under the naturalistic/interpretive paradigm, a different set of criteria is used to assess trustworthiness of research. Within the conventional positivist paradigm, the key research criteria are validity and reliability. Validity is concerned with whether the research measured what it was purported to measure while reliability refers to internal consistency and the long-term stability of the findings (Cheung, 1999). The set of criteria for judging reliability and validity of qualitative research is drastically different from the conventional positivist criteria. In other words, traditional notions of reliability simply do not apply to narrative studies, and validity must be radically reconceptualized (Mishler, 1990). Validation, the process through which we make claim for the trustworthiness of our interpretations, is the critical issue. "Trustworthiness" not "truth" is a key semantic difference: the latter assumes an objective reality, whereas the former moves the process into the social world (Riessman, 1993).

The following is a recapitulation of naturalistic and narrative research highlights focusing on four ways of approaching trustworthiness. Riessman (1993), claims each has possibilities but also problems.

1. **Persuasiveness** – whether the interpretation is reasonable and convincing. Persuasiveness is greatest, according to Riessman (1993), when theoretical claims are supported with evidence from informants' accounts as well as when alternative interpretations of data are considered.

2. **Credibility** – whether the findings and presentations are believable and authentic. Naturalist researchers delineate varieties of procedures in research design, such as prolonged engagement, persistent observation, triangulation, peer briefing, and member checking to establish credibility (Cheung, 1999). As the naturalistic paradigm holds that realities are multiple, the interpretation of the researcher may be different from the narrator (Cheung, 1999). Riessman (1993) refers to this procedure as "correspondence."

3. **Coherence** – how parts of an account are connected to make a meaningful story. Lincoln and Guba (1985) name this concept "consistency."

4. **Pragmatic use** – how useful the research is for similar endeavours. Most qualitative researchers refer to this concept as "transferability" (Lincoln & Guba, 1985). When researchers want to conduct similar research in the future, it is their responsibility to transfer relevant information to the study. The role of the qualitative researcher is to provide enough thick description and understanding of events and processes (Cheung, 1999).

5. **No canon** – validation in narrative studies cannot be reduced to a set of formal rules of standardized technical procedures. There is no canonical approach in interpretive studies, no recipes and formulas, and different validation procedures may be suited to some research problems than others (Riessman, 1993).

Narrative analysis, according to Riessman (1993), is not useful for large numbers of "nameless, faceless subjects." The method is slow and painstaking. It requires "attention to subtlety: nuances of speech, organization of a response, local contexts of production, social discourse that shape what is said and what cannot be spoken. Narrative

analysis is not suitable for investigators who seek an easy and unobstructed view of subjects' lives" (p. 69).

Rationale for using the quantitative scales for triangulation

Triangulation was not used in the traditional quantitative way to estimate error in measuring concepts but contributed to the completeness function of triangulation by providing explanatory insights from data from other sources. Jick (1983) terms this a holistic type of triangulation which enables the researcher to elicit data 'to which other methods would be blind' and suggest conclusions and to fill in gaps. A holistic approach contributed to the analysis by acting as a building block to deepen the understanding of the analysis of the qualitative findings.

Summary

There is much diversity in narrative research and no standard way of conducting analysis (Mishler, 1986; Riessman, 1993). But whatever the way, it is patterns of social relations that researchers are after (Franzosi, 2004). Whether the priority of analysis is structural, linguistic, or interactional depends on the researcher's purpose in the analysis. In my study, I used a triangulated design incorporating two complementary qualitative analytic strategies: (1) thematic analysis, and (2) content analysis. I chose Mishler's (1986) interactional narrative interviewing and Riessman's (1993) narrative analysis schema to conduct my narrative analysis (see Figure 4). I used thematic analysis (Agar & Hobbs, 1982) proposed by content analysis to analyze themes that emerge as a result of meaning-making processes that respondents experienced in their marriage.

Chapter Four

Orientation to the Findings and Discussion Chapters

Introduction

Chapter Four is an introduction to my four findings and discussion chapters, Chapters Five to Eight. I highlight the analytical dimensions of marriage institutional and relational, as well as the tripartite nature of commitment – personal, moral, and structural, to help conceptualize my findings. I discuss understanding the couples in the context of a diagnosis of dementia and draw attention to medication use to treat memory loss because all of my participants were enrolled in a clinical drug trial. I include the meaning of caring as it relates to couples experiencing dementia. I offer reflections from my pilot study as the dimensional concepts related to marriage and commitment were the result of further investigation resulting from my pilot study. I include the expected and unexpected advantages of the use of the quantitative scales for the study. Lastly, I discuss my preliminary model of the impact of commitment to the marriage relationship to the dementia experience.

Conceptual dimensions

"Truth is only and always a movable host of metaphors ... a sum of human relations"
(Nietzsche cited in Chambon, Irving, & Epstein, 1999, p. 33).

I adopted the analytical dimensions – institutional and relationship (see Table 2), and – the tripartite nature of commitment – personal, moral and structural – to help conceptualize the findings of my study on marriage commitment and the dementia experience. I did not use these analytical dimensions for dichotomous thinking in constructing difference in the analyses of the narratives. Rather, I considered them on a

continuum or in combination. Dichotomous thinking implies that most phenomenon are mutually exclusive and fit into 'binary' and 'oppositional' categories, in which one item of the binary is devalued in the relation to the other (Fook, 2005, p. 73).

Ties that bind: Models of marriage

The traditional view of marriage in Western societies is for starting a family, which usually serves as the building block of community and society. Thus marriage not only serves the interests of the two individuals, but also the interests of their children and the society of which they are part. Most people seem to feel that marriage involves some sort of permanent commitment, vaguely expressed in the text of most marriage vows. Commitment, most people seem to think, involves looking ahead to an entire life lived together, that it has a *permanent binding force* (Moller, 2005, p. 280). From a constructionist point of view, marriage is a social construction, an artifact of time, culture, and society. The foundational idea of social construction is profound according to Gergen and Gergen (2004), in that "everything we consider real is socially constructed ... nothing is real unless people agree that it is" (p. 10). In other words the world we see reflects our own internal frame of reference – the dominant emotions and wishes of our mind. We interpret what we are seeing from what we know of the world and our place in it.

Table 1. Two models of marriage (Reynolds & Mansfield, 1999).

Institution	Relationship
-Less freedom of choice of marriage partners	-Greater freedom of choice
-Marriage linked to wider societal and/or kinship obligations	-Marriage relatively separate from wider societal and/or kinship obligations
-Emphasis on economic aspects of marriage eg. property and the sexual division of labor	-Emphasis on the emotional and interpersonal aspects of marriage
-Public emphasis	-Private emphasis
-Marriage is one of a set of social relationships	-Marriage as the central adult relationship
-Relative inequality within marriage; patriarchy	-Relative equality within marriage; companionship
-Little relevance on mutual sexuality; sexuality linked to procreation	-Positive emphasis on sexuality; sexual dysfunction seen as sign of marital problems

It is generally agreed in long-term marriage literature that the "five Cs" are important elements that contribute to long term marriage satisfaction (Cheung, 2005). The five Cs are: (1) commitment, (2) caring, (3) communication, (4) conflict and compromise, and (5) contract, which refers to the marital partners' implicit and explicit expectations of each other and their marriage (p. 53). What seems to be agreed on within the last 50 years is the value attached to equality and sharing in modern marriage. However, many would argue that behaviour within marriage is still highly influenced by the institutional model of marriage. Fulfilling the roles of breadwinner and homemaker were considered the most important requirement of a successful marriage in 1955; by 1970, it was for husbands and wives to love each other (Reynolds & Mansfield, 1999, cited in *One Plus One*, 2006). Between 1980-2000 continuity and change, considered important to marital quality was reported by Amato, Johnson, Booth & Stacy (2003). Despite shifts in economic, demographic, societal and attitudinal characteristics of the married population for the past 20 years, remarkably little change in marital quality is reported in the literature, "representing a puzzle" to the authors (p. 19). In particular, the

reality of married life continues to be one of relative inequality around domestic duties. According to recent reports (Knudson-Martin & Mahoney, 1999), men still focus more on breadwinning and women focus more on childrearing and housework, particularly when children are in the house. Kulic (2002) studied marital equality and the quality of long-term marriage of 116 retired couples, and found that, on the whole, wives reported a higher level of burn-out and a lower level of marital satisfaction than did their husbands. Allen and Webster (2001) examined factors related to husbands' contributions to household labour when "wives get sick" and found that husbands who have egalitarian attitudes toward marital roles are happy in their marriage and do more housework.

The tripartite nature of marital commitment

When couples are asked what is important in their relationship the answer is often "commitment." But what does that mean? A key characteristic of enduring marriages is reported in the literature as commitment. Commitment in marriage is by definition considered to be a bond between husband and wife traditionally pledged during a wedding ceremony in front of witnesses. Commitment may mean the ability to renegotiate the relationship as changes occur (Robinson & Blanton, 1993). Stanley and Markman (1992) view commitment as encompassing two constructs, personal dedication and constraint commitment. Personal dedication refers to the desire of an individual to maintain or improve the quality of his or her relationship for the joint benefits of the participants. In contrast, constraint commitment refers to forces that constrain individuals to maintain relationships regardless of their personal dedication to them.

Johnson (1991) argues that the experience of commitment in marriage (the reasons to stay married) is not unitary – there are three distinct types of commitment,

personal, moral, and structural, each with a different set of causes, a different phenomenology, and different cognitive, emotional, and behavioural consequences. Personal commitment refers to the sense of wanting to stay in the relationship, moral commitment to feeling morally obligated to stay, and structural commitment to feeling constrained to stay regardless of the level of personal or moral commitment (cited in Johnson, Caughlin, & Huston, 1999, p. 160). These authors reported distinctions among the three types of commitment. The authors suggest that the tripartite nature of commitment has different causes and consequences and a measure of global commitment was essentially one of personal commitment only. In the analysis of the transcripts, I considered Johnson, Caughlin and Huston's model of the tripartite nature of commitment rather than viewing commitment as a unitary phenomenon. Three types of commitment and their components are detailed as follows:

1. **Personal commitment**: experienced as wanting to continue
   - Attraction to one's partner (love)
   - Attraction to the relationship (marital satisfaction)
   - Couple identity
2. **Moral commitment**: experienced as moral obligation to continue
   - Relationship-type obligations (divorce attitudes)
   - Personal moral obligation (partner contract)
   - Consistency values
3. **Structural elements**: experienced as constraint to continue
   - Alternatives
   - Social pressure
   - Termination procedures
   - Irretrievable investments (investments) (p. 162)

In a review of marriage, literature commitment can be described in terms of the degree to which couples intend to maintain their marriage (a) because of devotion to and satisfaction with their partner, (b) because of their belief in the sanctity of marriage as a sacred institution, as well as a personal obligation to honour their marriage vows; and (c) because of the desire to avoid financial or social penalties that might result in divorce

(Adams & Jones, 1997). Smedes (1986) suggests two old-fashioned reasons why commitment to endurance is the "guts" to commitment in marriage. The first reason is that marriage is for families, for having children, and caring for them. Second, marriage adds a dimension to our identity. And, if we annul this commitment, "we fragmentize the stories we are writing with our lives, we let loose of our past and chisel away who and what we are for the future. We lose a significant part of our own identity but what is worse, we rob the other person of the identity that our commitment promised to her or him" (Chapter 5, p. 3).

Understanding the couple in the context of a diagnosis of dementia

A couple's experience of questioning 'what exactly is going on' during the assessment period forms the context for a diagnosis of dementia. Generally, one or several of the following ten traditional warning signs are recognized by both spouses: (1) forgetting recently learned information or inability to learn new information; (2) difficulty with everyday tasks such as cooking and dressing; (3) inability to remember simple words; (4) use of inappropriate words when communicating; (5) disorientation to time and place; (5) poor or decreased judgment; (6) problems with abstract thinking; (7) putting objects in inappropriate places; (8) rapid change in mood or behavior; (9) increased irritability, anxiety, depression, confusion, and restlessness; and (10) prolonged loss of initiative. It is reported in the literature that most people with dementia found it helpful to have a diagnosis disclosed (for example 98% according to Van Hout, Vernooij-Dassen, Jansen, & Stalman 2006) but the incidence of disclosure is closer to 86% according to Vernooij et al, (2003).

Perhaps one of the reasons for a diagnosis being undisclosed is lack of awareness or denial on the part of the person with dementia. In this situation confrontation with a diagnosis may be very threatening (Seiffer, Clare & Harvey, 2005). Level of awareness is an important factor to consider when making decisions about how and when to share diagnostic information. Macquarrie (2005) suggests living with Alzheimer's disease should not be described as either denial or acceptance, but rather as a paradox of understanding that includes both acknowledgment and resistance. The research resulting from this study supports the authors' paradox of understanding. Whatever the level of understanding, a major theme in the lived experience of early dementia is "I want to be me" reflecting a desire to maintain a sense of identity (Harman & Clare, 2006, p. 484).

Alzheimer's disease is the most common form of dementia in the elderly (Cummings, 2004). According to the Alzheimer's Association (2006) a diagnosis of dementia involves a comprehensive evaluation that may include a complete health history, a physical examination, neurological and mental status assessments, and other tests as necessary, Skilled health care professionals can generally diagnose Alzheimer's with about 90% accuracy. Other conditions that can cause similar symptoms include depression, drug interaction, nutritional imbalances, infections such as AIDS, meningitis, and syphilis, and other forms of dementia, such as those associated with stroke, Huntington's disease, Parkinson's disease, frontotemporal dementia, and vascular dementia. Absolute confirmation of diagnosis requires a brain biopsy or autopsy. Even though the diagnosis of Alzheimer's dementia cannot be absolutely confirmed, new screening measures such as the TE4D-Cog are being evaluated and demonstrate great promise.

The TE4D-Cog, a new test for detecting early dementia of the Alzheimer type in English-speaking populations is showing promise as a dementia screening instrument (Mahoney, Johnson, Katona, Maxmin, & Livingston, 2005). The MMSE, the most widely used screening test, has pronounced 'ceiling effect' and can fail to detect dementia in individuals with high pre-morbid ability or education. It also generates false positives in people with little formal education (for example, eight of the thirty points depend on literacy/numerical skills). Therefore, one important advantage of the TE4D-Cog test is that the results are independent of age, gender and level of education.

Medication used to treat memory loss in dementia

Treatment for the signs and symptoms of dementia are available but as yet there are no interventions that prevent Alzheimer's or reverse the course. An emerging consensus suggests that the three keys to successful treatment of Alzheimer's disease are early detection, use of currently approved medications to provide symptomatic treatment, and development of medications to slow down or stop the progress of the disease (Solomon & Murphy, 2005; Peterson, 2003).[9] The first classes of antidementia drugs to gain approval were cholinesterase inhibitors (ChEls). These drugs act by enhancing synaptic levels of the neurotransmitter acetylcholine, believed to contribute to cognitive dysfunction, the central feature of Alzheimer's disease (Hagerty, Lingler, Martire, & Schultz, 2005). The three main drugs in this group that are licensed for mild to moderate stages of Alzheimer's disease are donepezil (Aricept), rivistigmine (Exelon), and galantamine (Reminyl). The most recent drug to be launched for use in Alzheimer's

[9] It is estimated that only half of the people treated with these drugs will benefit. People with behavior problems show the most clinically significant benefit. The drugs can continue to benefit the person with Alzheimer's disease for up to 18 months, although some people may benefit longer (Howcroft, 2005, p.14).

disease with similar benefits to the others, but also licensed for use in the severe stages, is memantine (Ebixa) (Howcroft, 2005). According to Solomon and Murphy (2005), approximatlely 25% of patients diagnosed with Alzheimer's disease are treated with antidimentia drugs. Most clinical investigators involved in drug trials believe that by the time the clinical diagnosis of Alzheimer's disease is made, enough damage exists to the neurons of the brain that reversal of the condition would not be possible (Peterson, 2003).

Caregivers play a critical role in the diagnosis and treatment of patients with Alzheimer's disease. For example, caregivers' around-the-clock access to the behaviour and their intimate knowledge of the patients' functioning have led researchers to view these individuals as proxies of choice for measuring noncognitive outcomes in antidementia drug trials (Hagerty, Lingler, Martire, & Schultz, 2005). Patients and their caregivers face an ethical challenge when deciding whether to enroll in a clinical drug trial, because Alzheimer's disease impairs decision making (Hirschman, Joyce, James, Xie, & Karlawish, 2005).

All six couples participating in the research were referred to me through the memory assessment clinic. Five were participants in an Alzheimer's clinical drug trial. With the exception of the Campbells, all other couples were accepted in the start-up of a new 18 month, global phase 3, Alzheimer's disease trial for the drug ***Flurizan*** (Myriad Pharmaceutical Company). The purpose of the study is to evaluate the changes in cognitive ability and activities of daily living in patients with Alzheimer's disease as measured by specific evaluations during 18 months of dosing. The inclusion criteria for participants eligible for the drug trial fit with my inclusion criteria for my project on commitment in marriage and the dementia experience. For example, patient inclusion criteria include:

- Have had a diagnosis of probable Alzheimer disease's disease.
- Men or women aged over 55 years and living in the community at the time of enrollment.
- Signed the Subject Informant Consent Form (ICF) and is willing and able to participate for the duration of the study.
- Able to read and understand English (Dutch, Danish, Flemish, French, German, Italian, Spanish or Swedish) to ensure compliance with cognitive testing and study visit procedures.
- At least six years of education, or sufficient work history to exclude mental retardation.
- Adequate vision and hearing to participate in study assessments.

Subjects must have a reliable caregiver who can read, understand and speak same language. http://www.clinicaltrials.gov/ct/show/NCT00322036

The meaning of caring

Walker and Dickson (2004) argue that the examination of illness-related talk in marriage is an excellent forum for identifying the relational culture in marriage. The authors claim 'illness scripts' elucidate the couples' co-constructed relational culture; the private world of rules, understandings, meanings and patterns of acting and interpreting. In their study five distinct couple types emerged: (1) the sympathetic couple; (2) the independent couple; (3) the mixed couple; (4) the nonreciprocal couple; and (5) the rejecting couple. Findings from the study suggest that couples have different strategies for handling minor health problems. The rejecting spouses engaged in nonsupportive and non-nurturing illness caring behaviours. In contrast, spouses in the sympathetic couple type displayed highly nurturing and caring illness behaviours for each other. "When spouses' relational expectations are met, they are more likely to reciprocate the caring illness behaviors for their spouse" (p. 542).

The meaning of caring, the exact nature of care-giving, and the dilemmas of the carer and cared for are not simple to untangle. Dalley (1988), in *Ideologies of Caring,* suggests, for example, at the affective level, a distinction can be made between 'caring

for' and 'caring about'. The first has to do with the task of tending another person; the second has to do with feelings for another person.

The mixing of the caring functions (for and about) has implications for both parties in the caring relationship. Both find that the affective relationship of caring about each other becomes complicated by overlaying of the 'caring for' relationship. Love, in this context, often becomes fractured or distorted by feelings of obligation, burden, frustration (Dalley, 1988, p. 10).

Research on the impact of early dementia on the marital relationship is limited. Few studies attempt to combine the perspective of the people with dementia and their partners as this study does. More to the point, limited research in this area highlights the need to better understand how couples make sense of and adjust to a diagnosis of dementia and the impact that has on their marriage relationship. For example, Baikie (2002) found changes in marital intimacy and marital satisfaction. Changes resulted from reduced shared activities, loss of emotional support from a spouse, and a diminution in the quality of verbal communication between the couple. Robinson, Clare and Evans (2005) found that couples described a period of joint negotiation and adjustment in acknowledging losses and also recognizing resilience and coping strategies. This process allowed couples to maintain and reconstruct their sense of self as an individual and in relation to their spouse.

As more and more couples face a diagnosis of early stage dementia together it will be necessary to look beyond individual factors relating to access to services, and consider the impact of a framework for service delivery that includes relationship-based models and those emphasizing socio-cultural understandings (Mahoney, Cloutterbuck,

Neary, & Zhan, 2005; Pratt, Clare, & Kirchner, 2006: Mernoij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006).

Reflections from the pilot study

I have decided to enter my journal notes from my visits with "The Campbells" who acted as the pilot for the study. The use of the dimensional concepts of traditional and relational models of marriage, as well as the tripartite nature of commitment, were the result of research done to help me understand this couple's commitment to their relationship.

The following are my field notes from the first home visit to the Campbells. I have included a key theme of my feelings from the visit and titled them as *harmony in the family.*

> *I was met at the door of an upper class residential home in a distinctive area of the city by an enthusiastic talkative spouse and greeted as a special guest. Her spouse faded into the background and allowed her "centre stage" for the initial greeting. He directed me to the dining room table and we sat while his wife chatted, repeating the story that she had been born left handed like her father and that he had allowed her to use it, unlike his experience where he was forced to use his right. She commented often about having the word "obey" removed from the wedding vows. There was a strong women's rights allegiance in her family history. She had a social work degree. She is able to write with both hands and that has made it easy for her because she writes down all phone messages while talking on the phone. She was a school teacher and was able to write on the blackboard with both hands, which amazed her students.*
>
> *I explained the project and provided a background on myself and my connection with the Clinic. We discussed the consent form and both spouses signed. Mrs. C. needed encouragement to stay focused and finish the questionnaire. She seemed to enjoy the opportunity to tell stories although I do not believe she was aware of just how often she repeated them. The couple claimed to be "over educated" and report a privileged family history with "intellectual opportunities of a high order." Political appointments, medical doctors of note and acknowledged academic excellence rooted in a prestigious university were reported from both spouses.*
>
> *Mr. C talked about his brother's wife who also had Alzheimer's disease. He said that the wife was "a dark black cloud all day." He courageously cared*

for her for seven years. All the mirrors in the house were covered and she thought strangers had entered as she walked past them. "It was horrible." Mr. C made coffee, we talked about his garden, and he showed me his extensive art collection. They were both involved with the church and their community.

Mr. C reported that he was extremely unhappy when asked to describe the degree of happiness with his marriage, all things considered, in the questionnaire. That did not fit with my early observation. I did not observe a loving relationship but a very respectful one. I wondered what his extremely unhappy feelings were all about? He was very successful, engaged with his grandchildren, with their cottage, he was still consulting, and going on vacations together with his wife and usually a grandchild. (Journal notes from March 22, 2006)

Both spouses seemed committed to the institution of marriage. Dementia presented a major disruption to their marriage biography. The second home visit was a taped interview starting with me asking the couple to tell me how they met and married - their wedding story. The following are my journal notes from that visit and the theme from that visit is: *the family setting is critical.*

The visit went very well. We were all more relaxed. The couple really enjoyed talking about their wedding. They even brought out their well-worn wedding album to show me, pointing out who people were and what positions in life they eventually attained. "Ours was a high society wedding they remarked; they did not have to do the planning. About 300 guests were invited. They were married in a United church with a traditional service and wedding vows of "love and honor" but not "obey." The couple reported a stable successful family history of marriage with the proper attitudes instilled in them as children. Their parents acted as role models. They learned the "rhythms of life" early on, the responsibility of children and society. Mrs. C said she appreciated that he never phoned home to say he was bringing someone home for dinner. Mrs C was congenial and traveled with her husband on professional trips. The couple talked about having four well educated successful professional children, and now their children excel just as their grandparents and parents to maintain the family place in academic and social excellence.

(Journal notes from April 10, 2006)

The third home visit was a taped interview and my plan was to start with me asking the couple about the events leading up to a diagnosis of dementia. Instead, Mr. C was anxious to share a story of a crisis in their relationship. The theme for this visit was: *the turning point.*

Mr. C had "given a great deal of thought to our last interview" and wanted to talk about two things. He wanted to talk about a difficult time in their marriage when his wife lost her first baby to crib death. This brought them close together as a couple. He was much more open to talking about this time in their married life. He also talked about friends dropping off for his wife. He also wondered if I got the information I needed to write up a good research paper. He wondered if I would make changes to questions that would have made it easier to focus on an answer. He really wanted me to interview their home cleaner and friend for 17 years, (which I did). He also wanted to know if I wanted to interview his children. If so, he would set that up as well. Mr. C had been a student advisor and researcher, publishing 75 articles. (Journal notes from April 12, 2006)

The expected and unexpected advantage of the use of quantitative scales

"Facts and data may be convincing at one level and irrelevant at another"
(Hawkins, 2002, p. 283)

The expected purpose for the use of quantitative scales in the study was to gain a better understanding of couple's consensus to experiences on issues relating to satisfaction and adjustment to his or her marriage over the years. Issues related to commitment, caring, communication, conflict, compromise, and marriage expectation were deemed related to marriage satisfaction and adjustment. The individual scores were compared to the couples' narratives, produced together, to gain a deeper understanding of how the role of the past defines the present situation, and the experience of dementia.

The quantitative scales were relevant to my understanding of and introduction to the couple-in-relationship and a barometer to the awareness of the spouse experiencing dementia. For example, in my first home visit interview with the Campbells, Mrs. Campbell had difficulty answering the question "*How many children do you have*?" "*How many children **do** we have,* Dave*?"* In other areas of the questionnaire about the marriage relationship, she had no problem answering the questions. I got the sense that these questions often made no sense to her. Some of the questions she did not answer, for

example, questions about sexual relations/affection. Her difficulties seemed to be with short-term memory; she repeated the same stories over and over, she was disoriented to time, she needed constant cueing by her husband to stay on task, not wander to new topics, and to finish the questionnaire. However, she did finish, and felt very proud of herself as she handed it back to me "*There she said*", with a satisfied smile on her face.

What I gleaned from the couple's relationship was a sense of mutual respect, patience, understanding, and wanting to say and do "the right thing" for the sake of the research project. The couple was well educated, the husband himself involved in research for many years. He asked me at the end of the interviews if I thought I had asked the right questions. "*Your research is only as good as the questions you ask*", he said to me. I did a great deal of thinking about that comment, reading the transcripts, and did make some changes in the way I conducted my next interviews. I was more spontaneous with probes, I would ask, "*What kinds of difficult times did you experience in your marriage?*", and then add, "*Were there any crises*?" The two responses were often different.

The couples did leave out questions that seemed to make no sense to them, asking me, "*What does this mean*?", or "*How do I answer some of these questions when true or false does not apply*?" The answers to several questions were particularly helpful in the analysis of the transcripts, confirming several hunches, and helping me solve some inconsistencies with responses. For example, Mr. C. reported on the questionnaire as being extremely unhappy in his marriage. His wife reported being very happy. I sensed there was a very strong moral commitment to their marriage relationship – Mr. C. **cared about** his wife deeply, but **caring for** her now that she had dementia was very difficult.

Conceptual framework of the analyses

The conceptual framework laid out in Figure 6 is a guide to my findings in the following chapters. The content of the framework in Figure 6 was deduced from my initial reading of the narrative texts of couples along with my extensive literature review on the topic.

This model depicts the preliminary findings from reading the couples' transcripts. It suggests that history and culture play an important role in the couples' commitment to marriage. Commitment to marriage seemed to focus more on the institutional model, where moral and structural commitment were more evident or on the relational model where personal commitment is more of a focus. A couple's relationship biography develops over time with the dimensions of commitment, caring, conflict, decisions, roles, and satisfaction impacting the relationship. A diagnosis of dementia sets into motion the caring aspect of the relationship. Caring *for* seems to relate more to the personal commitment to the relationship, and caring *about* refers more to the moral and structural. The caring style impacts marriage quality or happiness. Marital happiness is reflected in commitment to the marriage relationship.

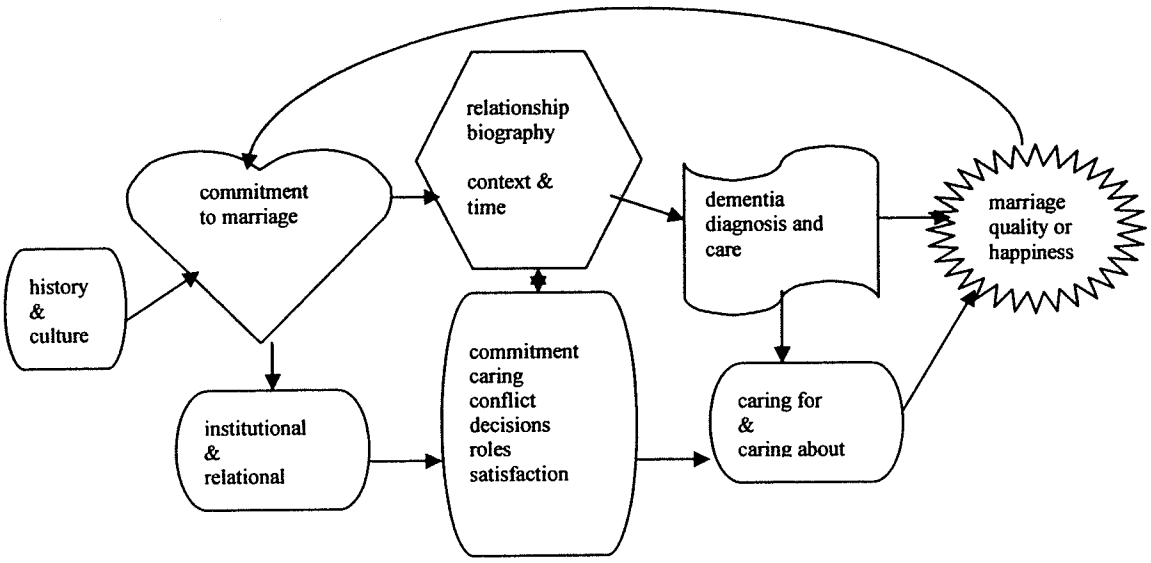

Figure 6: Impact of commitment to the marriage relationship on the dementia experience: Preliminary findings.

In Chapter Five, I present the married couples who participated in the research interviews. A profile of my impression of each couple's construction of marriage provides a backdrop to their introduction. I explore a couple's stories of meaning of commitment in marriage within a social and cultural context and how they co-enact their marriage commitment.

In Chapter Six, I discuss each couple's response to the meaning and experience of early-stage dementia to their marriage relationship through three phases of the transition process; pre-diagnosis, diagnosis, and post-diagnosis.

In Chapter Seven, I discuss how couples reappraise and reconstruct meaning through changes in the marriage relationship after a diagnosis of dementia. Particular emphasis is placed on how couples integrate dementia into every-day life. I define this integration by understanding the caring relationship, changing roles and responsibilities,

changing relationships, and future plans. Marriage quality and satisfaction relating to the DAS scores and ROR scores, as well as Commitment to the Spouse, are discussed with regard to marital satisfaction and commitment.

In Chapter Eight, I conceptualize the commitment factors which contribute to sustaining dementia care. I discuss the findings along the lines of four factors which contribute to commitment in marriage, which I derived from the couples' stories of what marriage means: (1) partnership for life; (2) reciprocity; (3) resilience; and (4) forgiveness. I then reformulate my conceptual model of the co-enactment of commitment to the marriage relationship on the dementia experience and its relationship to symbolic interactionism.

Chapter Five

Findings and Discussion: Meaning of commitment to the marriage relationship

"Humans constantly construct meaning; it is part of being human. We construct and reconstruct our world and who we are in the process." (Gubrium & Sankar, 1994, p. 53)

Introduction

Marriage relationships are based on commitment. The historical and contextual bond found in the marital relationship influences how dementia is encountered and lived. Relationships as described in the couples' narratives and biographies allow us to understand dementia and its effects on the interaction pattern of spouses. Spouse carers have meaning systems in their interaction with their spouses which have been formed and refined over the years. Their present role and their motivation to care can be seen in the context of their previous relationship, regardless of whether it was close and compassionate or not. Marriage biographies are retrospective and prospective reflections. Emotional subjectivity in marriage creates a biography with a shared view of reality. Understanding commitment to marriage as a shared view of reality is the focus of this chapter.

This chapter begins by introducing the married couples who participated in the research interviews. A profile of my impression of the couples' construction of marriage will provide a backdrop to their introduction. Next, the couples' stories of meaning of commitment in marriage within their social and cultural context will be highlighted. Each couple's experience of getting settled into married life will be discussed under the narrative themes of 'tough times/hard work' and 'family history is important'. Finally, this chapter will highlight the development of three themes which were seen to link the

narratives of 'doing things together', 'overcoming difficulties', and 'reciprocity', to explain how couples co-enact their marriage commitment. References have been included in the findings section when previous research findings apply and directly support significant details and events related to the interactional nature of the data. The quantitative scales (DAS, ROR) are reported, and further discussed in detail in Chapter 7.

A general profile of respondents

For this study, six married couples were interviewed and were comprised of *four* married couples with the *female* diagnosed with Alzheimer's dementia and *two* married couples with the *male* diagnosed with Alzheimer's dementia. The years of marriage ranged from 44 to 60 years. Four of the couples were born in Canada, while the other two couples were born in Germany and England respectively. All four of this latter group arrived in Canada in their early teens to early twenties. All couples were Protestant and married in churches with traditional wedding services.

The ages of the husbands ranged from 68 to 83 years, while the wives' ages ranged from 65 to 80 years. All but one affected spouse would be considered having late-onset Alzheimer's disease. One wife would be considered having early-onset Alzheimer's disease, as her symptoms started before 65 years of age. All of the couples had two to four children (see demographic information).

The educational background of the couples ranged from grade 5 education to university education. By their education backgrounds and occupations, four couples were middle class. Two couples were upper class. Three spouses, two male and one female, had university degrees with a professional designation. One male was a prominent

professional and the other male a prominent consultant. All spouses but one had retired. One male worked part-time in his consulting business.

Two of the females worked outside the home after their children were grown up and four had never worked outside the home since they married. The four females and two male spouses were formally diagnosed with early dementia of the Alzheimer's type at a memory assessment clinic.

Table 2. Demographic information

Name	Campbells	Burns	Gladstones	Martins	Smiths	Peters
years married	55	52	56	46	60	44
age AD *	F - 80* M - 82	F -72 M -77*	F -77 M – 83*	F - 65* M-70	F -79* M -81	F -72* M- 68
children	4	4	3	4	3	2
Education years or university	F - U M - U	F- 12 M- U	F- 12 M- 12	F - 10 M - 10	F - 7 M - 10	F-12 M -5

Summary impressions of the six couples' construction of marriage

In order to facilitate the reader's understanding of the six couples, I offer a brief discussion of my impression of how these couples constructed their relationship in ways

that contributed to their commitment to their marriage. I have added a specific strategy or theme that impressed me with each couple.

The Campbells

The ***family tradition couple*** with high *moral commitment* to marriage

The Campbells were married in a United church in 1951. They had a "high society wedding" with a traditional service. They had four children approximately two years apart. Mr. Campbell, a professional, was mostly uninvolved at home in the early and middle years of marriage. The wife made decisions for the family and planned the family's social life. A maid helped with the housekeeping and children. Early in the marriage the wife lost a child at 71 days, an event that brought the husband and wife together as a couple. At the time of the interview the husband did all of the family decision-making and monitored his wife's whereabouts at all times. Together they still enjoyed gardening, cultural events, their summer cottage, and their affiliation with the United Church. The wife's reason for getting married was to have a family and children, and she found someone she loved and respected. The wife's reason for staying married was because she and her husband had similar interests and because he took good care of her. The husband's reason for getting married was because it was the natural thing to do, and marriage was a strong family tradition. The husbands' reason for staying married was because there was a strong tradition of good marriage, children became a priority, and he had a successful career. The wife's ROR was 12/25 and her DAS was 126/151. The husband's ROR was 10/25 and his DAS was 143/151. The husband reported being extremely unhappy and the wife as being very happy in the DAS. The couple's scores suggested both spouses were highly satisfied and adjusted in their marriage relationship and their gender role orientation was between egalitarian and traditional (see page 202).

The Burns

The ***resilient couple*** with high *personal commitment* to marriage

The Burns were married in a United church with a traditional wedding service in 1954. They had four children, three girls close in age and a son born five years later. The husband was a general manager of a company and uninvolved in the care of the children and home. His interests provided the couple opportunities for an active social life during the early to middle years. The couple had "tough times" during the late middle years of marriage when the wife battled cancer and the supporting treatments, family deaths, and a call from her husband's office about her husband's interest in a red-haired girl. The husband had a business loss and lost a lot of invested money. At the time of the interview the husband helped with chores around the home with direction from his wife. The couple enjoyed time with their children and family who all live in the city. The reason the wife married was because of love and wanting to spend their life together. The reason she stayed married was the same but added he had been a good husband. The husband did not answer the questions but commented it was love at first sight, and that she was the girl he was going to marry. The wife's ROR was 8/25 and DAS was 112/151. The husband's ROR was 12/25 and DAS was 124/151. Both husband and wife reported being very happy in the DAS. The couple's scores suggested that both spouses were satisfied and adjusted in their marriage relationship and their gender role orientation was egalitarian (see page 202).

The Gladstones

The couple ***living together but living separate lives*** with a high *structural level* of commitment to marriage.

The Gladstones were married in a church in England in 1950. They had a large wedding with a traditional service. They had three children close in age. The husband was an accountant and mostly uninvolved with the children and home. He was responsible for family finances and at the time of the interview he was still managing the family books. The couple moved long distances several times during their early years of marriage to accommodate the husband's career. The wife made friends easily and became involved in the social life of the communities they moved to. She found the moves difficult as she was never a part of the decision making in selecting the move or their future home. She found it difficult to leave friends behind and pack up the children. The couple reported they got married because they loved each other and stayed married because they never thought of leaving. The couple had many wonderful vacations and enjoyed lawn bowling. The wife went back to work after the children were grown and bought herself a red sports car which to her represented independence and freedom. She remained involved in gardening, community groups and volunteering. Her husband enjoyed badminton and working on the books. At the time of the interview, the couple's relationship was confrontational. The wife had taken on the role of mother as she now needed to remind her husband to get up, to eat, bath and dress. She also dealt with behaviour issues related to anger around spending money on a broken television. The wife admitted that she was a little unhappy in her marriage that she had many disappointments and upsets over the years while the husband reported being happy but difficult to live with. The husbands ROR was 11/25 and his DAS was 81/151. The wife's ROR was 20/25 and her DAS was 81/151. The couple's scores suggested that there was a low level of adjustment and satisfaction in their marriage relationship and their gender role orientation was traditional (see page 202).

The Martins

The loving couple ***living-in-partnership*** with a strong *personal commitment* to marriage

The Martins were married in a Baptist church with a traditional wedding service in 1960. They have four girls close in age. Both spouses had immigrated to Canada in their early teens and experienced hard times adjusting to life in Canada. The husband was determined to "get ahead" (make money) by working hard and wisely investing in property. Although the husband was a busy consultant, he remained involved with the children in the early and middle years of marriage. The wife did the household chores, and "together" the couple made decisions for the family and planned their social life. The couple travelled extensively with their children and enjoyed cottage life in the summers. The couple experienced the tragic death of their second daughter when she was run over by a big truck. The couple's belief in forgiveness helped them make sense of the accident. Later in life the wife had a serious cancer operation that resulted in depression and her giving up f a new business she had then recently established. The husband was steadfast in his devotion and support at this time. At the time of the interview, the wife was doing odd jobs around the house under the husband's step-by-step directions. The husband did the cooking and monitoring of his wife's confusion. Together they still enjoyed reading the newspaper, gardening, travel, family activities, and their affiliation with the Baptist church. The wife's and husband's reasons for marriage were because they loved each other. The reason why they stayed married was the same. The husband and wife's DAS was 120/151. They decided to work on the questionnaire together as the wife was not able to understand the check system for the answers. The husband's ROR was 13/25 and the wife's ROR was 12/25. The couple reported being fairly unhappy in the DAS. The couple's scores suggest that both spouses had a high level of satisfaction

and adjustment to the marriage relationship and that their gender role orientation was traditional (see page 202).

The Smiths

The couple seeking ***"the good life"*** with commitment to *reciprocity* in marriage

The Smiths were married in a United church with a traditional wedding service in 1946. They have three children close in age, two girls and one boy. The husband was a carpet layer, working long hours and mostly uninvolved in the care of the home and children. The wife worked as a department store manager and, with the help of a babysitter, managed the home in the early and middle years of marriage. The couple made decisions together. They went camping with the children in the early and middle years and traveled by camper extensively after retirement. Both husband and wife experienced hospitalization during the later years. Each spouse responded by visiting the other all day and bringing special meals to share in the hospital. The couple's reason for getting married and staying married were because they loved each other. The couple decided to fill out the marriage questionnaire together because the wife found the questions difficult to understand. I ended up reading out the questions and asking the couple to select an answer. The couples DAS was 140/151. The couple's ROR was 12/25. They both reported being very happy with their marriage. The couple's scores suggested that both spouses were highly adjusted and satisfied with their marriage relationship and that their role orientation was traditional (see page 202).

The Peters

The ***compromising*** couple with strong *religious commitment* to marriage

The Peters were married in Calvary Temple in 1962. They had a small wedding with a traditional service. They have two sons close in age. The couple moved to the country to raise their children. Early on, the husband worked as a mechanic in rural towns in Manitoba, eventually building a family home, and was uninvolved in the care of the home and children. The wife enjoyed community life in a small town and managing a large garden, the children, and home. The couple experienced difficulties in their relationship during transition times when circumstances forced them to make changes in their day-to-day life. At the time of the interview, the husband helped with the housework and cooking meals. The wife had become fearful of socializing and leaving her home. The couple enjoyed going to church, country rides in the car, and visits from their grandchildren. The wife's reason for getting married was to have a home and family of her own. The reason she stayed married was because her husband was a good man to be with. The reason the husband got married was for companionship. The reason he stayed married was commitment to the vows that they made to each other. The wife's DAS was 117/151 and her ROR was 11/25. The husband's DAS was123/151 and his ROR was 11/25. The husband reported being very happy and the wife reported being perfect in the DAS. The couples score's suggested both spouses were midrange in their adjustment and satisfaction in their marriage relationship and that their role orientation was midrange between egalitarian and traditional (see page 202).

Understanding the couples' marriage relationship in their social and cultural context

Society is symbolic interaction

"*Society is social interaction that is symbolic, that is characterized by cooperation, and that develops culture.*" (Charon, 2004, p. 164)

Simon and Marcussen (1999) suggest that peoples' beliefs about marriage which are personal and individualistic are also shaped by their **cultural** circumstances and also reflect broader cultural themes and content. Culture then consists of many factors that aid in our understanding of marriage relationships and the commitments spouses make to each other and to the relationship. The values or standards of expectations for married couples, the beliefs or things couples believe to be true, as well as the language, dress, rites, and ceremonies are all elements that in one way or another shape how couples view themselves, the world they live in, and their place in it. Therefore, it is impossible to understand couples without grasping their cultural foundations (Johnson & Grant, 2005). One definition of culture by Johnson and Grant (2005) is defined the following way:

> Culture is historical, bound in traditions and practices passed through generations; memories of events – real or imagined – that define a people and their worldview. (Culture) is viewed as collective subjectivity, or a way of life adopted by a community that ultimately defines their worldview. (p. 15)

According to Charon (2004), a 'shared culture' is any instance of ongoing social interaction that is characterized by cooperation among actors and that creates a shared culture. Society then, creates culture. Charon conceptualizes society as shown in Figure 7.

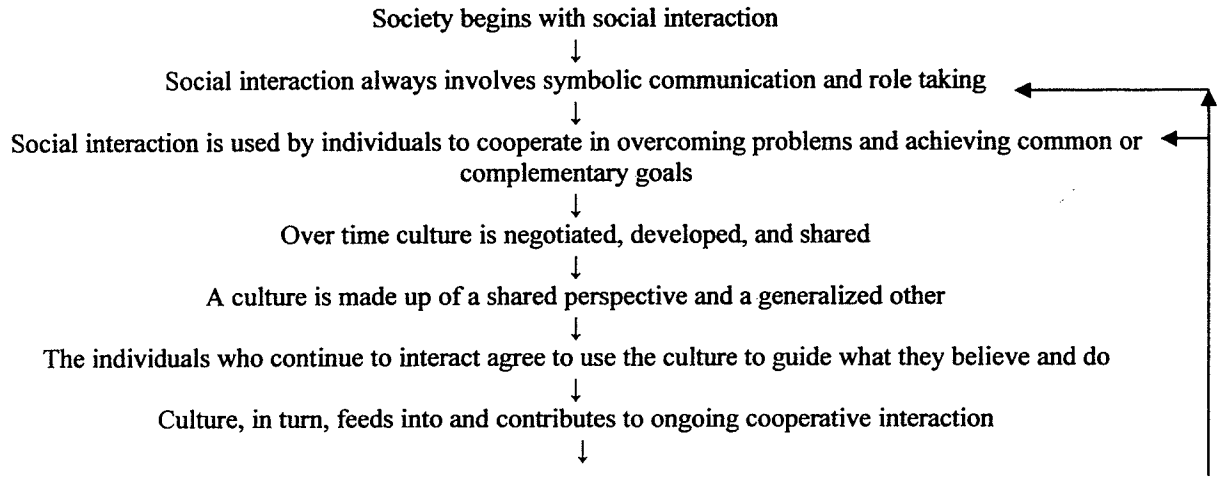

Figure 7: The conceptualization of society (Charon, 2004, p. 169)

During the 1950s and 1960s, Katz and Briger (1988) argue the way of life adopted by many communities was the nuclear family. During this time families underwent a process of specialization through which emotional and socialization functions were being improved. The authors state that during the 1970s and 1980s things started to change. Divorce rates soared and the negative impact of modern values and behaviour patterns (related to alternative intimate lifestyles) on the stability of marriage and the future of the nuclear family were evident.

The couples participating in the research project were married in or very close to the 1950s. This was considered by many to be the "golden age of the family," a time when nuclear families were envisioned, divorce was rare, and family values were traditional. A review of family life in the 1950s will provide a backdrop for understanding the social values, beliefs, and culture of the couples at the time of their marriages.

Marriage and family life in the 1950s

"The family domain contains a sense of shared history and future and a sense of 'biography'. When we marry, we enter a process of 'biographical fusion' in which we not only share experiences but increasingly share a common way of typifying and explaining those experiences." (White & Klein, 2002, p. 77)

According to Golan (1981), the transition from single to married status usually starts with what she calls "marital readiness." She goes on to say that theoretically a person will be ready for marriage or couplehood when she/he feels able to enter into a shared intimacy that includes sexual enjoyment and commitment; show capacity for tenderness and affection for the other person; display interest in that person's emotional condition and personal adjustment, indicate a readiness to emerge personal plans for the future; is willing to share economic problems and be realistic about ability to contribute to the maintenance of the joint household; and to be able to delay personal gratification in order to meet the needs of the other and to build the relationship (p. 67). Marital readiness in the 1950s was influenced by the beginning of what was called "the golden age of marriage" (Coontz, 2005; Kiernan, 2004) across many Western nations. In the 1950s the growing emphasis on romance merged with the postwar consumer economy to create a major wedding industry. Coontz (2005) reported that wedding ceremonies, considered traditional in the 1950s and 1960s, came "off the rack", so to speak. Almost everyone married, often at an early age. Marriage at that time was considered as much a union of two gender roles as of two individuals. At this time social roles were clear cut. Wives were to be homemakers. Husbands must be breadwinners. As a result, Coontz suggests most 1950 weddings were conventional from the vows to the music to the cake decorations. Weddings were variations of the same theme, depending in part on how much money was available.

A major tenet of the life course perspective (Mitchell, 2006), is that a young adult's developmental path is embedded in, and transformed by, conditions and events that occur during the historical and geographical location in which he/she lives. A young adult's choices, such as when to marry, when to have children, and roles and responsibilities in marriage are all impacted by the social and cultural traditions of the time. Relationships in marriage, then, are structured by social understandings (White, 2005). Insight into the historical stereotypical "1950s" family structure and lifestyle will provide a backdrop to understanding the social and cultural ideologies reflected in marriages at the time.

For many Canadians, the 1950s represented the cultural symbol of nostalgic "traditional" family life. With World War II behind them, Canadians felt safe and secure. Middle class Canadians began to move to suburbs in pursuit of their dreams. Nice houses, pleasant neighbourhoods, with neighbours functioning as extended family and where there was often no need of locking one's door was the stereotype for family life in the 50s. Under these conditions the atmosphere was ideal for raising children. The husband generally assumed the role of 'breadwinner' and the wife assumed the role of full time mother. The following is an excerpt by Lori Anderson (Marriage and Women) from a 1950s high-school, home-economics textbook, on how to have a happy husband:

> *Have dinner ready, plan ahead, even the night before, to have a delicious meal – on time. This is a way of letting him know that you have been thinking of him and are concerned about his needs. Most men are hungry, when they come home, and the prospect of a good meal is part of this warm welcome needed.*
> *Prepare yourself. Take 15 minutes to rest so that you'll be refreshed when he arrives. Touch up your makeup, put a ribbon in your hair and be fresh-looking. He has just been with a lot of work-weary people.*
> *Be a little gay, and a little more interesting. His boring day may need a lift.*
> *Clear away the clutter....prepare the children...minimize the noise...have a cool or warm drink ready for him...listen to him...make the evening his...*

In 1995, Tom Fennell from Maclean's Magazine featured an article titled *The 1950s: Looking Back at the Booming Decade,* in a series marking the magazine's 90th anniversary year. I have selected several excerpts, as follows, from that article to highlight salient historical events and trends of the decade of the 1950s:

- As the 1950s began, the Canadian soldiers who had returned home victorious from the Second World War were rebuilding their lives. They hoped that the jobs that the postwar boom had brought were permanent, and that the Great Depression, which had disappeared during the war, was just a bad memory. There seemed no end to prosperity.
- The country's gross national product doubled to $36 billion in the decade and the nation's newfound confidence triggered a baby boom.
- Two Prime Ministers, Liberal Louis St. Laurent and Conservative John Diefenbaker, had to deal with the emerging threat of a nuclear war, while at home a quiet revolution was stirring in Quebec.
- One of the biggest "events" in anyone's life in the 1950s was taking possession of one of the shiny new automobiles that were looking increasingly futuristic in design.
- Television, like the car, was considered a status symbol in the 1950s, and the CBC TV network launched in 1952.
- The nation's economy was increasingly dominated by U.S. interests. Historically, Britain had been the major customer for Canadian goods. By 1956, Canada was exporting 60 per cent of its industrial output to the United States.

- The cultural makeup of the country also shifted in the 1950s. The vast majority of Canadians now lived in urban areas. New immigration meant that more people of non-British or French origin were moving to Canada.

The author concludes by suggesting that for all the changes that took place, the fifties would soon seem a simple, innocent time in comparison to the turbulent decades that would follow.

A socio-cultural understanding helps the researcher learn the rules, values and norms that influence decisions and guide peoples' choices. As Rubin and Rubin (1995) contend, understanding what the interviewees are saying during open-ended topical interviews requires the researcher to learn the rules, norms, values, and understandings that are passed on from one generation of group members to the next. As the authors point out, "for many people, explaining to others what they ***ordinarily do*** can be difficult, as such routines, are taken for granted and rarely examined or thought about" (emphasis added, p. 169). I found this to be the case when interviewing participants about their marriages. They often did have trouble describing day-to-day events in their marriage relationships. For example, when asking about roles and responsibilities in marriage, couples often assumed a taken-for-granted understanding on my part. For example, Mrs. Gladstone commented on roles and responsibilities "*Oh, you know, I did this and he did that, the traditional stuff.*" As Gee (1991) argues, the retold narrative will be shaped and embedded in the larger narrative context coming from the history, traditions, socialization, and the narrative groups people share stories with. To look then at an event outside of a narrative, or a narrative outside a wider narrative context, or a narrative context outside the social traditions, history and practice of a group of people is both according to Gee "misleading and pointless" (Gee, 1991, p. 3).

Understanding the meaning of commitment in marriage

In the structural analysis of the transcripts from the joint narratives, all six couples' stories would be considered a "romance." In a romance heroes face a series of challenges en route to their goal and eventual victory and the essence of the journey is the struggle itself. I consider the narratives to be "progressive narratives" (Lieblich, Tuval-Mashiach & Zilber, 1998) as the stories advance steadily. There are structural similarities between the narratives in that they are stories of couples who adapt. Events or turning points that could have been considered worthy of upsetting the equilibrium appear to be taken in stride. All couples face a major crossroad or turning point in life when one spouse is diagnosed with Alzheimer's dementia.

In this section I begin with the couples' wedding stories. The next section will reflect on common themes during the early years of settling into married life; tough times hard work, and family history are important.

Wedding stories...Marriage is for life

All couples married in their early twenties after at least a year (and in most cases longer) of courting. All couples were married in churches between from 1949 to 1960. Their marriage service, included traditional wedding vows, based on the traditions of Western civilization. Marriage in this context is considered a relationship that is predicated on a mutual and voluntary commitment to life-long, monogamous partnership (Pinsof, 2002). Additionally, they commit to staying married for life by taking an oath before God, repeating the *Solemnization of Matrimony* to each other, witnessed by their

wedding guests. The oath goes as follows: *I (name) take you (name) to be my lawfully wedded husband/wife:*

> *To have and to hold,*
> *from this day forward,*
> *for better or worse,*
> *for richer or poorer,*
> *in sickness and in health,*
> *to love and to cherish,*
> *till death do us part.*
> The Book of Common Prayer (p. 301)

The responses to my question of "*What kind of commitment did you make to each other?*" were unanimously agreed to be the kind of commitment couples made to each other in the words of the oath or wedding vows they took. The six couples' marriage biography stories suggest a major global theme with respect to commitment in marriage – *marriage is for life*. Not one of the couples suggested they had ever thought of or discussed divorce during their long-term marriages of more than 30 years. In fact, none of their friends divorced. All couples had elements of a traditional and relational view of marriage (as described earlier by Reynolds & Mansfield, 1999). The most common views of the *relationship model* of marriage were the relative equality within marriage meaning "companionship", as well as an emphasis on the emotional and interpersonal aspects of marriage. A consensus within the *traditional model* of marriage was linked to a wider societal and/or kinship obligations. Couples believed *marriage was for life* and this included an obligation to their children that they stay together.

The global theme *marriage is for life* reflects the tripartite nature of commitment by the six couples. The tripartite nature of commitment was described earlier by Johnson, Caughlin, and Huston (1999), and includes personal, moral, and structural elements of commitment. One couple's story, the Campbells, demonstrated a strong moral

commitment to marriage and a lesser personal commitment. Two couples' stories, the Martins, and Peters, demonstrated a strong personal commitment and an equally strong moral obligation. A fourth couple's story, the Burns, demonstrated a strong personal commitment to marriage. The remaining two couples, although in agreement with commitment meaning marriage is for life, were unable to articulate the meaning as clearly. For example, the Gladstones, who express a strong structural commitment to marriage, referred to the traditional vows of the times as what commitment meant. Mr. Gladstone, expressed it in this way, *"They just meant what you said. You're supposed to stay married and that's it."* Similarly, the Smiths had difficulty expressing what commitment meant. Mrs. Smith responded "*to always be together anyway, for sure.*" The following are shortened wedding stories of the Martins, the Peters the Campbells, and the Burns. The couples' stories reflect their view in the belief that *marriage is for life.*

The Martins' story

Both Mr. and Mrs. Martin were immigrants from Europe; he was 17 and she was 13 when they arrived in Canada. They met when Mrs. Martin's family rented part of the Martins home. The couple spent time together in a church youth group, and driving together in the evenings while studying English. Mr. Martin was hard working and achievement oriented, and at 19 years of age managed to save $1000 for a down payment on a house. At that time CMHA had incentives for young couples where they would lend up to 85% of the value of a house with sweat equity. On the application form for signature was a line where it said, "*Your wife's name.*" He was not married at the time and not interested in getting into a "long-term relationship" with a person. "*So I struggled with what name to put down, then finally, I looked into my heart and I said,* 'Sara

Krutzen". Sara was fifteen. She had been noticing Mr. Martin and claims she did things *"in a way that you can see what they're like...and that's how I found him."* The couple connected at church and Mr. Martin showed Sara the house and said, *"My conscience was bothering me, and I says, you know what? I used your name, for this purpose."* Mr. Martin went north to work to earn money to help pay for the couple's wedding. Four years later the couple married. In reflecting back to the wedding service, I asked the couple about the vows they made and the commitment made to each other. The Martins expressed their answers in the following way:

J: What kind of commitment did you make to each other?

Mr. Martin: We had to attend marriage classes, so the two of us saw the Pastor...and he basically said what it means to get married and from our family tradition, that was the way we looked at it. So it was nothing spectacular for us that you marry and ***you marry for life****. Now if you do have some difficulties, and you do have and will have, barriers to communication as a factor. As a Christian, you sit down and work it through. You have to give and take, and use the example of Christ as being, so to speak, the Mentor. When we then were basically decided on a date that we would get married, he then said one thing, and I remember that. And he says, this couple, you as a couple, are made for each other. It's not because you have chosen, but God has chosen, and that was a pretty strong guideline for us in our, in our relationship, and so when we then said the normal Christian vows that we are for...*

J: Better for worse.

Mr. Martin: For better and for worse, and on and on. It was a natural, natural thing that we would do and that's what we believed in. And so, we can honestly say that that guided us, our relationship, and I think (wife's) as well. She can speak for herself.

Mrs. Martin: Well yeah. I mean we've been together long enough to sort of, at that plateau, we haven't seen things the same. But together, we also come around. We don't segregate. We don't separate. We're together.

The Martins entered marriage thinking of it as a life-long covenant where commitment was viewed as fidelity for life, for better or for worse, till death. In this view, a covenant is a pledge that is to be honoured regardless of the other person's

behavior. The Martins view their marriage relationship as a partnership. Viewing marriage as a partnership where couples have an equal say is evident in Mr. Martin wanting his wife to speak for herself.

The Peters' Story

The Peters also entered marriage with the view that commitment to marriage was for life. The Peters met when Mr. Peters' brother married Mrs. Peters' sister and they were best man and bridesmaid. A friendship of two years turned into marriage. Mrs. Peters remarks, *"And we were together so much that I think we sort of discussed it rather than ask each other...he was a nice guy. He was lots of fun to be with...he had the same beliefs that I had."* They had a traditional church wedding with 80 to 90 quests. When asked about their wedding vows and what commitment meant, they responded in this way:

J: What does commitment mean to you?

Mr. Peters: Commitment, it means dedication.

Mrs. Peters: Through thick or thin, you hang in there, cause nobody's perfect. When there's a little discussion between us or we get sort of upset a little bit, well just normal I think, you gotta think, you know, we're two different persons. We can't make him like I think he should be because he's himself. Or he can't make me somebody, you know, outside myself. I mean there's always that. There's certain things in a person you cannot change. What you see at first, that's what you're gonna have. When you get older it might get better or a little bit, you know.

Mr. Peters: Yeah, well, when you talk about commitment, that's staying true to what you've said, eh, the vows, and you're gonna follow that wedding vows, and like (wife) says, how can you change a person? Yeah, you might change him a little bit but you won't change him drastically that they're gonna be a completely different person or personality will be totally changed. That doesn't happen.

There is a high level of agreement between Mr. and Mrs. Peters in their view of the important characteristics of personal commitment to each other and a moral

responsibility to the institution of marriage. The Peters are able to understand the importance of taking the role of the other and find meaning in social interaction when they get upset with each other. Mrs. Peters was able to express her experiences and took the lead with this question Unlike all the other interviews, with this couple Mrs. Peters who is diagnosed with Alzheimer's dementia, "held the floor" for approximately the same length of time as her husband. She was often philosophical about her views of marriage and dementia. She told me often how shy she was throughout her marriage and anxious in social situations. After the final interview was over and I was saying thank-you and goodbye I remarked "You sure were not shy today", and she replied, "That's cause I felt comfortable talking to you." She also made me feel comfortable by her engaging positive attitude towards me in answering the questions during the interview. I appreciated her ability to articulate her experiences of living day-to-day with dementia, the impact it had on her, as well as her family and friends.

The Campbells' Story

The Campbells met when Mr. Campbell was invited to Mrs. Campbells' home to be introduced to her sister. The families were from the same privileged background and setting up introductions between the children of these families was common. Mr. Campbell was much more intrigued with his future wife than with her sister. The couple dated while attending university and married when Mr. Campbell was in his last year of residency. Mr. Campbell went to great lengths to set the backdrop for his marriage story. He provided me with an overview of life in high society Montreal in the 1950s. He structured his character in the narrative as a morally responsible man of integrity that "did his duty" when family members needed care. The couple brought out their well-worn

wedding album and together we reviewed the pictures and I received a brief biography on the significant members of the wedding party and selected guests. They proudly reported that many of the guests and members of the wedding party are listed in a "who's who" in Canadian book. Several past political leaders, respected leaders in medical research etc. were among the mentioned. I was unfamiliar with Victorian high society lifestyle. For example, the couple talked about Mrs. Campbell's "debutante ball", a formal ball to announce her eligibility for marriage. It was important for the analysis of the Campbells' biographies to have a better understanding of this historical period of their lives. In the following excerpt, the Campbells express their view of commitment to marriage as a moral responsibility.

Mr. Campbell: Ours was a high society wedding. We did not have much to do with the planning. About 300 guests attended. We were married in a church in Montreal with a traditional service and wedding vows of love and honour...

Mrs. Campbell: Not obey! My mother was the president of the National Council of Women and a true women's libber, so the word 'obey' was not in the vows.

Mr. Campbell: We have a stable successful family history of marriage with the proper attitudes instilled in us as children and our parents acted as role models. We recognized the rhythms of life early on... the responsibility of children and society.

Mr. Campbell went on to say that they had four successful well educated professional children, and now their children excel just as their parents and grandparents to maintain the family place in academic and professional excellence. Throughout the interviews, Mrs. Campbell would repeat the same stories over and over. Often the stories were not related to the questions. Mr. Campbell was always respectful and polite and would gently prompt his wife, evoking her memory, suggesting the answer to interview questions, but not taking credit for answering them directly. Mr. Campbell always positioned his wife in the best possible light. Getting along, and doing things for each

other, including mutual respectfulness and politeness formed the basis of their cooperative relationship, throughout their long-term marriage.

The Burns' story

Mrs. Burns first met Mr. Burns in the summer at the lake when he tried to pick her up, *"(Sam) tried to pick me up and I got very nervous cause I knew he was considerably older than me and my girlfriend and I ran home."* Three years later they were at the same party and they formally met. Her husband remarked that she had worn a red dress, a marvelous outfit, and he sat looking at her and said to himself, "*I'm gonna marry her.*" He told me she had guys "*whining all over her*", so he "*finally had to get rid of them.*" They started dating the following summer and the summer after that they married. By then she was 18 and he was 22. The couple had a traditional wedding service in a church followed by a dinner and dance with 150 guests. When asked about the commitment they made to each other during the wedding service, the Burns responded with the following comments:

Mrs. Burns: Just the way it was written in the church ceremony...well till death do us part, for better, for richer for poorer, for better for worse. You know, all those things.

J: And that was absolutely what you believed?

Mr. Burns: And we're still here.

Mrs. Burns: And what we said, what our vows were in church, which was the traditional wedding, is exactly what we meant. As I said the last time, it was a commitment, and you have to live up to your commitment. I mean first of all, you're not, nobody chose (Sam) for me and nobody chose me for (Sam). We chose each other.

Mr. Burns: I tried to.

Mrs. Burns: We chose each other, so you don't take a commitment like that lightly, and it is a commitment. As I said earlier, I dated quite a few different boys but I knew that none were going to be my husband.

J: How?

Mrs. Burns: Well, I had a little trick. I would say to myself, do I want to wake up and see him at the breakfast table every morning for the rest of my life? Even at that point, I answered to myself, no, then I knew that that guy wasn't going to get to first base with me...I didn't have any qualms with (Sam) getting to first base.

The Burns presented themselves as a couple who never fell out of love with each other over the years of struggle and victory. Bachand and Caron (2001) suggest a long term-happy marriage is a matter of two people who have a shared understanding of what their marriage means to them. Similar backgrounds, friendship and love were general themes emerging in their qualitative narratives on happy long-term marriages.

Getting settled into married life

"*Becoming a couple is one of the most complex and difficult transitions of the family life cycle.*" (Walsh, 1982, p. 178)

Walsh (1982) speaks of newly married couples renegotiating roles in the transition to marriage. Marriage requires that a couple renegotiate a number of personal issues that had previously been defined by themselves or their parents from where to eat, sleep, have sex, or fight, to how to celebrate holidays or where and how to work, live, or spend vacations. Marriage also affects personal relationships. The couple must renegotiate their relationship with their parents, siblings, relatives, and friends in view of the new marriage. The period of *getting settled in to married life* requires three sets of interlocking developing tasks to be carried out according to Golan (1982): his, hers, and theirs. The new husband needs to continue to develop as a young man and establish his occupation, to assume his responsibilities for support of the family, to develop competence in his role as sex partner, to begin to share his intimate thoughts and feelings

with his wife, to participate in setting up and running the household, and to engage in mutual social and leisure time interests and activities.

According to Golan (1982), the new wife along with personal development also has the responsibility for running and managing the home, and learns to improve her homemaking skills. She is often expected to carry her share of financial responsibility by starting or continuing work. She also needs to develop her competence as a sex partner, to communicate effectively and intimately with her husband, and develop relations with her in-laws and husbands extended family. Together the married couple must establish their marriage as a functioning unit by starting on their basic developmental tasks as a family. This would include developing mutually agreeable ways of managing the household, their relationships, and perhaps planning for children.

Tough times, hard work

"*So we starved and struggled and we had a lot of fun, though. Made a lot of friends and Mary had all the children she wanted and I was studying like crazy.*" (Mr. Campbell, p. 12)

I asked the couples to tell me about the history and satisfaction of their marriage in the early years. In the structural analysis of the couples' narratives, a theme of *tough times/hard work* was identified. The couples told stories of struggle with not having much money to live on, mostly expressed by wives, and working hard putting in long hours, mostly expressed by husbands. The couple seemed to be satisfied with their marriages in the early years, although several mentioned that it was a big adjustment. Most couples married young, and the early years were more often than not a time of trying to make

ends meet. Most of their friends experienced the same financial stresses, so it was considered normal to have to start married life with the bare necessities.

In the following narrative Mrs. Burns talks about the early years of marriage, and the experience of struggle.

J: What about the early years then?

Mrs. Burns: Oh, struggle

J: Really? How so?

Mrs. Burns: Well, (Pete) didn't make much money, and I think as I said, when we were first married, now (Pete's) mother was a divorcee and she raised him on her own and it was tough. She worked at Eaton's and that was it, and I had a very secure home life. But when we were married, now (Pete) always worked but we didn't make much, and it was not more, like you know, (Beth) was born. We were married in June one year and our daughter was born in July the following year, so we weren't really very well established but, so we lived, we moved back in with my parents for a year. And then Dad lent us the money for a down payment on a cute little house and never missed a payment. (Pete) paid steady as anything, every month, and we didn't have a car. We lived a long way from the bus, but anyway, we managed, and I always, oh and I did ask (Pete) when we were expecting (Beth), do you want me to be a stay-at-home mom or do you want me to work? And immediately he wanted me to be a stay-at-home mother because I think you missed having your mother at home, did you not? Yeah! So that's the way we did it.

The Peters also talked about the early years of marriage and struggle.

Mr. Peters: The early years, it's getting settled into married life.

Mrs. Peters: Yeah, it's different, very different.

Mr. Peters: And building your own home too. That's part of it. Everything gets rushed. Those days, I mean, you worked long hours, especially in the trade that I was in, long hours, weekends, everything.

Mrs. Peters: Oh my god, a kid the first year.

J: Children?

Mrs. Peters: Yeah, our oldest son was born within...

Mr. Peters: Eleven months.

Mrs. Peters: Eleven months after we were married, so like I say it's in the first year. And that was a little hard for me because as a girl just married, trying to make a home. We really didn't have, we rented then, and here all of a sudden before you know it, you're pregnant. I had to go through that and I didn't have a mom to go and ask her a lot of questions cause I hadn't even...I knew there were a lot of things that could crop up, so I had to start right from scratch on my own sort of thing, and he's take me to the doctor when needed.

With the arrival of the Peters' first child, the couple experienced the transition from being a married couple to being parents with their own family. The couple talked about how they eventually moved to the country and built their own home so their two children would have a big yard to play in. Both Mrs. and Mr. Peters were raised in small friendly rural communities and they wanted their children to grow up in a safe environment with a strong emphasis on church, family, and community.

The Gladstones also encountered tough times in the early years of marriage. They arrived in Canada four years after marriage when Mrs. Gladstone was three months pregnant, after 3 or 4 miscarriages. This time "he hung on" through the flight and the couple set up the first of many homes in a trailer. Mr. Gladstone was hired by a firm to help in design at a construction site. Due to the nature of his job, the couple would move frequently. Just as Mrs. Gladstone would settle into a new community, they would be off on another move. She built up tremendous resentment towards her husband during all of those moves. A common theme throughout the couple's narrative was Mrs. Gladstone's declaration that she wished she had more choices in the marriage, especially when it came to moving and housing. "*Oh I cried when we left Halifax. I just loved it. I'd go back on my bare feet to the east coast. They threw a huge party when we left and I cried all the way through it*" (003, p. 9-10). In the following segment the couple talk about their first housing experience living in a trailer:

Mrs. Gladstone: Well first 4 years we actually lived in a trailer, so and a lot of the construction people did. They had construction sites and they'd hook them up to electricity and we actually had running water. (Laughing) I didn't have running hot water for the first four years of married life.

Mr. Gladstone: (laughing) It was a big change for her. She was, she had a very nice house in England, and of course her father was pretty well off. He was a very big general practitioner. So I say, I often think, not often think but sometimes think what a change it was in Sally's life.

All of the couples made the transition to parenthood during the early years of marriage. Most became parents within the first year or two of marriage. The couples adjusted well to married life and as they moved to the middle years, they enjoyed financial stability, they all bought a homes, their children grew up, and they began to face different struggles associated with their children and/or their health. Although the theme *tough times/hard work* focused on one particular life event in the couples' relationship it was important. The successful transition to marriage and parenthood suggests that the couples' beliefs about their new social roles, were influenced by broader structural socio-cultural factors supporting marriage and the family.

Family history is important

Mr. Campbell talked at great length of the importance of family history in understanding commitment in marriage. He believed the "*family setting is critical.*" The couple commented, "*We had a stable successful family history of marriage with the proper attitudes instilled in us as children and our parents acted as role models. We recognized the rhythms of life early on, the responsibilities of children and society.*" Almost all family scholars would agree with Mr. Campbell that the family of origin is tremendously important. Mr. Campbell suggests an important social role of the family is to prepare individuals for adult life. This means responsibility of children and society and

instilling in children the attitudes, skills, and experiences that will help them develop successful adult relationships. The Campbells multigenerational dynamics within the family of origin constitute a legacy.

The multigenerational dynamics of the Campbell family left a legacy of relational patterns of interactions that were transmitted to the Campbells children and grandchildren by influencing the emotional and social development of children. Mrs. Burns also talks of the importance of family history as she believed her strong sense of commitment came from her parents. Her fondest memories as a child were waking up and hearing her parents talking to each other at the breakfast table. All of their four children are with their original spouses. Her husband suggests, "*Maybe they're using us as a pattern.*" Mrs. Burns responded, "*They all married young people that their marriages lasted ...so, I don't know whether this is something that you pass on or it's something that draws you to someone.*" Mr. Burns was very insightful with his comment that perhaps his children used them as a pattern for success in marriage. Again, the Burns were able to identify the impact of family history and the successful pattern of interaction that they passed on to their children.

Mr. Gladstone did not have a positive family experience in growing up. He remembers little of that period in his life as he left home at an early age. He was willing to admit a poor family history with insistence from his wife. Mrs. Gladstone was relentless with her negative comments about her husband not wanting to talk about his family throughout the interview:

Mrs. Gladstone: You should explain you came from really an unhappy home life. If you ask (Peter) whatever you like about his growing up, and he says, I don't remember, don't remember, don't remember.

J: That's what you just don't want to remember, or don't remember?

Mrs. Gladstone: Or don't want to.

Mrs. Gladstone: But you didn't ask. I asked and asked and asked you. Well find out. Who are they?

Mr. Gladstone: I don't know why.

J: You don't know why?

Mrs. Gladstone: Because he was terrified of his mother. She would give you hell.

Mr. Gladstone: Yeah, She was very positive, no doubt about that, or negative.

Mr. Gladstone: I mean my father, the marriage wasn't very good, and he was 27 when he was an injured captain in the army, and she was 19 and I don't think she had much relationship with men. I don't think so. Things collapsed when I was about 3... Well, my parents weren't well off together, that's for sure. I don't think I knew what to do as a married man.

Mrs. Gladstone: Finally after a few years, I said, when you die, I'm gonna have it written on your tombstone, I never asked. To this day.

Mr. Gladstones awareness of his experience during his early years and the fact that he believes he did not know what to do as a married man are profound indications of the ability of individuals with dementia to "think" and derive meaning from early experiences. In all fairness, Mr. Gladstone really did not know a great deal about his family of origin. The importance of family history, values and beliefs were different for this couple, as they were not shared. They came from different socio economic backgrounds and that seemed to undermine adjustment to married life. Sensing this frustration I asked the following questions:

J: So, if I was to ask you the thing you liked most about your wife, the thing you appreciated most about your wife, what do you think it would be?

Mr. Gladstone: She's been very nice to live with.

J: And what would you say? What is the thing you most appreciate about your husband?

Mrs. Gladstone: I'd say he's very reliable, yeah.

J: Would you do it again?

Mr. Gladstone: Yes.

Mrs. Gladstone: Oh boy. I think I'd ask an awful lot more questions. I didn't realize there was an awful lot (Peter) wasn't telling me.

Another important aspect of family of origin will be discussed under family history in Chapter 6. One common theme within the couples' families of origin was a predisposition to dementia of the Alzheimer type. This finding is consistent with current literature on the topic. There is a strong hereditary factor in both early and late onset dementia of the Alzheimer type.

The co-enactment of the marriage commitment

"*We made our choice early on and we are still happy together, we have a partnership, we share everything.*" (Journal notes from the Burns)

Commitment in marriage is acted out by the husband and wife. From a symbolic interactionist perspective, couples interact in marriage, they communicate with each other, take on roles, cooperate and problem solve. The couples' definitions of commitment in marriage shifted from a symbol of the wedding vows to something that had endured. To grin and bear it, for better or for worse, is what committed couples do in marriage. In this section, the couple's responses, their feelings, beliefs and insights into the questions regarding their roles, responsibilities, and satisfaction in marriage and what it is like to be a couple are discussed. 'Developing the marriage partnership' was identified as the main theme in this section and was supported by three sub-themes: (1) doing things together; (2) working through difficulties; and (3) reciprocity.

A marriage is a dynamic relationship that changes over time with each spouse bringing into the relationship his or her beliefs, values, and expectations about marriage (Sharlin, Kaslow, & Hammerschmidt, 2000). The couples' personal and subjective views of satisfaction, happiness, and marital health develop through their life experiences, family relationships, social contexts, economic situations, and personal attributes (Sharlin, Kaslow, & Hammerschmidt,). The research couples believed in the institution of marriage; they were committed to their partners. Their shared marriage experience and marriage beliefs influenced their evaluation of commitment and its reconfirmation as detailed in Figure 8. They expected that there would be tough times but also expected good times. Most spoke of their marriage as a partnership and viewed the development of that partnership as a key element to their marital commitment.

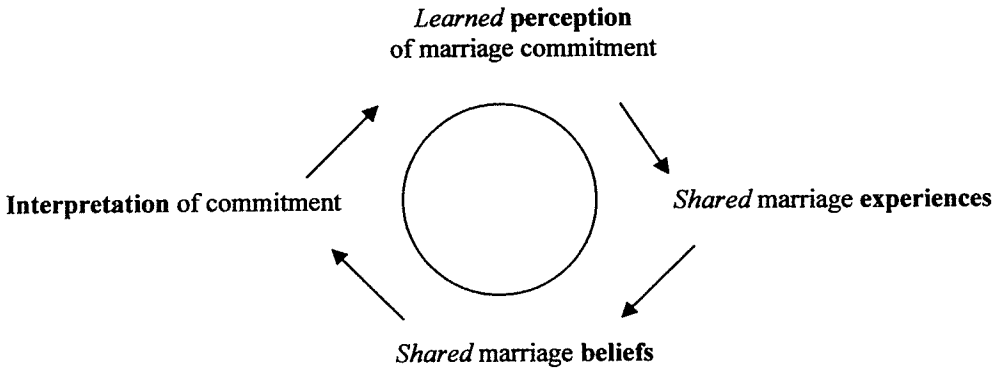

Figure 8: Influences in the commitment cycle

Over the years, various relationship variables related to partnerships have been proposed as important to happy long-term marriages. Togetherness, considered a maintenance strategy, is one such variable that has been touted as instrumental to a

quality marriage. Togetherness is described by Graham and Bassett (2006) as a sense of two people operating as one in a relationship. Conversations with spouses then are referenced with 'our' and 'we', with closeness and camaraderie, joking and caring about each other (p.341). The use of maintenance strategies have been linked to stronger perceptions of marital commitment (Rusbult & Bunk, 1993 cited in Communication Reports, 1999).

Doing things together

The Burns and the Peters referred to *doing things together* as an important aspect of being a couple as they suggest in the following. The Burns' response:

J: So, what's it like to be a couple?

Mr. Burns: Marvellous. We do things together. We like the same things.

Mrs. Burns: Pretty much, yeah, pretty much.

Mr. Burns: We spend a lot of time together.

Mrs. Burns: But we have two TV sets. (Laughing)

Mr. Burns: We have lovely children, and we spend a lot of time with our grandchildren.

Mrs. Burns: We've always had a lot of friends as well. We always enjoyed entertaining.

The Peters' response:

J: So, what is it like to be a couple?

Mrs. Peters: It's great. I think it's great.

Mr. Peters: Well, we do so much together, like...

Mrs. Peters: Yeah we were not apart too much, okay, and I think that's maybe a plus for us.

Mr. Peters: Like the things we do, we both enjoy, we both enjoy the outdoors...and I guess in marriage as a couple, the common things you share, if you can share common

things, then you've got something in common. If both of you have your individual interests and you're always split apart, I can't see that lasting. I think that's an important area in a marriage, in a couple's life, that common interest, eh?

The Burns and the Peters, as well as the other four couples, talk with fond memories of enjoying camping or time spent at their summer cottages with their children. The couples talk about enjoying gardening and the outdoors as so elegantly put by Mr. Campbell:

But with the families on each side, and Sunday night dinners, and going to the lake in the summer, and you see, ***we're driven by nature.***

Later on in early retirement and after the children had left home the couples talked about traveling together. The Campbells and Martins now travel with their grandchildren. Mr. Martin talked about how, to this day, he and his wife have breakfast together every morning and had done this all their married life, with no exceptions. He said to his daughter that having breakfast together was an example of acting out commitment in marriage.

Mr. Martin: Through all our life, through all our life I think, I can't recall ever that I would have breakfast by myself, ever. When I was up, she would be up, to either make my breakfast for me or make lunch while I was getting ready to go to the office or to work, she would be ready to do that, and then she would look after the kids, as they had to get up after that. So when I said that to one of my daughters, I says, you want to keep a good marriage, this is how your commitment is. Well, she took it serious, but then she says, it is hard. I says, and that much more I appreciate my wife. She had 4 children, or 5, she was up in the morning with me to get ready, for me to get ready. It's not that she wanted me to be out of the house, but to be with me and we had a moment together, and I appreciate that. And we still, we still do that you know.

Mr. Martin describes partnership and commitment motives in marriage as those that express the continuing process of give and take, making the effort to share moments together, and appreciate each other.

Mrs. Gladstone focused on her disappointment with housing throughout the interview. She claims she had to live with houses her husband picked out because he

always moved first and she would pack up after the school year with the children. She even hated the current house she was living in when her husband purchased it. Many years later Mrs. Gladstone found her dream home close to where they lived. Her husband said no, they could not buy it. He never even went to see it. There was no give and take in that situation. She held that against him to this day as described in her narrative.

Mrs. Gladstone: Well once we moved into this house, which was an absolute horror, it was, oh God it was awful. I've kept some of the wallpaper cause I know people won't believe it if they seen it. And I did actually see after some friend of mine told me about this house, on the corner of, it was on (street), corner of I don't know. Absolutely gorgeous and this woman met me at the door cause we used to have a Corgi, and she met me at the door with 2 Corgis, and I thought this is meant. This is meant, you know, this is my house. It was absolutely gorgeous and the fellow who was selling it was a lawyer and he said, we have to make it a private sale and I'll do the work so there'll be no charge to you and on and on, and it was absolute, oh it was just perfect. So I waltzed outside and (Peter) says no, we're not having that. I'm thinking what, what? Oh God. He just doesn't like, I don't know. Doesn't like to move.

Mr. Gladstone: It's a lot of work, that's why.

Mrs. Gladstone: What? To move?

Mrs. Gladstone: Excuse me. Excuse me while I have a little talk with her (meaning me). Usually he goes ahead because the contractors, you know, okay we need you. He goes. I move. I have moved time and time ...yes.

Mr. Gladstone: I'm sure I was wrong. I'm sorry.

Mrs. Gladstone: You were wrong.

I asked the Gladstones about the good times in their marriage. They agreed that something they enjoyed doing together was going on yearly holidays overseas. They were in New Zealand, South East Asia, Fiji, Thailand, and several other interesting destinations. When asked if there was anything else they enjoyed doing as a couple, they said lawn bowling.

Overcoming difficulties

Difficult times were experienced by all couples in one way or another. For the Campbells and the Martins it was the tragic death of a child. Mr. Campbell talked about the event as the biggest stress they had as a couple.

Mr. Campbell: The biggest stress we had was our first child. The tot died at 71 days of age and let us figure out life, and we were quite happy to keep on going together and that was gonna be overcome. A lot of our understanding of how to deal with one another flows out of that.

J: Can you just tell me a bit more about that period of your life?

Mr. Campbell: Well, see, remember, we, (Mary) stopped working in the beginning of her pregnancies and the first pregnancy was a boy. His name was (David), and he seemed to be just fine but then he suddenly died abruptly in his bed, which was a cot death, a very common pediatric problem. They now manage it by having the children look at the ceiling, I guess, all the time. They don't put them prone, but that stressed our life, and a lot of, we came to realize we were gonna do a lot of good things together.

The Campbells had a large emotional support system of friends and family who aided in moderating the stressful situation. In fact Mrs. Campbell talks of her friends who had babies would ask her to come over and see their baby only after their babies were bigger that David had been. So she explained, "*When I held another baby in my arms it wasn't like holding (David), and I just rejoiced in the fact that they had a healthy baby.*" The Campbells went on to have three children each a year apart. The nurses in the hospital were interested to know if Mrs. Campbell knew anything about birth control, and she reminded them to look at her records, and they would then understand that they had had some troubles land. She let the nurses know that "*she was gonna have the babies she wanted and when she didn't want anymore, she would be careful to make sure she didn't have any more.*"

Mrs. Campbell was able to articulate how she overcame a very difficult time in her life, with the loss of her baby. In fact, there was clarity of long-term memory unlike her recent memory of events. She was able to narrate her own story of the experience. The couple overcame the difficulty and moved closer together as a couple.

The Martins also experienced a catastrophic event in their lives when their 7 year old daughter was run over by a truck:

J: Tell me about the history and the satisfaction of your marriage relationship. Maybe the early years.

Mrs. Martin: Well the early years, I guess those were the most important ones, I suppose. We had four children, actually 5, one is not with us anymore, and it was a very taxing time during that time when we had the accident.

J: Can you tell me what happened?

Mrs. Martin: She was, how old was she when she?

Mr. Martin: She was 71/2 years old.

Mrs. Martin: 71/2 years she loved to ride her bicycles and she was all over the place, and she drove too far with the bike and a car came.

Mr. Martin: It was a truck. It was a big truck. Yeah, it was a big truck.

Mrs. Martin: And she had a fairly large bicycle, which I didn't know she was taking it, and she, the pedal got caught into the curb and she fell onto the street and she was dead. Well, that was a very...

J: I am so sorry.

Mrs. Martin: It was very traumatic for us, and otherwise we would have had five children right?

Mr. Martin: You did have five children.

Mr. Martin: I think it was, it was also, she was driving with the next, the second oldest daughter and (Marcia), was always very concerned about the well-being of (Emily). So she would say to (Emily), '(Emily) watch this big truck', and then she passed her and

while doing that, she lost control, and like (wife) said, and she fell and the rear tire went over her head. And she called me, it was, I wanted to basically die.

J: I can't imagine.

Mr. Martin: It's just impossible to think of it, yeah.

I was so overwhelmed at the Martins' recounting of the story of their child's death that we all sat in silence for awhile. We were crying. I later told them how much I appreciated them telling me about Emily. They said they had not talked about the event in a very long time. One thing that struck me is how Mrs. Martin was able to articulate the event with such clarity. Her word finding capacity was compromised in most of the interview responses.

When I asked the Burns about the history and satisfaction of their marriage, Mrs. Burns responded that they had a couple of "rough spots" just like any couple. She went on to tell me about Mr. Burns' business going under. It was at a time when interest rates were 24%, her husband had invested in a business of their own - an equipment dealership, and the interest rates "killed them" and they were forced to sell off at a loss. Those she said were rough times. I asked if there had been any crises in their lives besides the business issue and Mrs. Burns told her story:

Mrs. Burns: There was one little, and that was also that same year, that the business, that was the year that, well everything happened that year. First of all, our son got married and this sounds really silly, then my cat died. And you were phoning that, and you were a little bit taken with that red-headed girl at work, and they, yeah. That was tough. I don't know whether anything ever actually came of it, but it was close. So there was a big disappointment there. Then my brother died. It was just one thing after another, that whole year, and as I said, the business went belly up, or had to sell it off. We didn't go bankrupt, but had to sell it off. So all those things, but we survived them.

The couples interviewed overcame their difficulties because they had made a lifetime commitment to marriage, they were loyal to their spouses, had strong moral

respected their spouses as best friends. As Mrs. Burns points out they survived the rough spots, although it was tough, and there were a lot of disappointments along the way.

Reciprocity

The couples in this study demonstrated through their narratives consideration and sensitivity in their roles and responsibilities as husband and wife, and considered the roles equivalent. According to symbolic interaction, rules of behaviour for positions is a major characteristic of roles (White & Klein, 2002). The study couples believed in the traditional role of husband as breadwinner and wife as homemaker. They understood the rules, clarity and expectations of those roles. The couples did minimize the relevance of conflict in their present stage of life as well as over their life course together. This is consistent with Dickson, Hughes, Manning, Walker, Bollis-Pecci and Gratson's (2002) study on conflict in later life in long-term marriages. They reported that present-day conflict patterns are consistently different from how couples managed conflict earlier in their marriage.

Mrs. Smith was the exception to the rule as she worked outside the home as a retail manager after their last child turned 8 years of age. The couple shared the roles and responsibilities of home and family. Mrs. Smith described how in the winter time her husband would go to the parkade at her place of employment and he'd turn her car on so it would warm up before she left for home. They admitted to "set-to's" but nothing serious, friendly arguments such as, *"Why weren't you home in time for supper?" (laughing).* Mr. Smith said "*I stopped off and had a couple of beers.*" *(laughing).*

The Peters talked about differences of opinion in marriage but considered it normal.

Mrs. Peters: The whole trouble is, he's usually right.

Mr. Peters: And the thing is, and that goes from everything, from your activities, your sexual life and everything, that incorporates everything. You always have differences of opinions and you have to work through those, and those difficulties are still here today. They don't change.

J: The differences you had early on are the differences you still have?

Mr. Peters: Oh sure, they're there, but you know how to deal with it, eh?

J: For example?

Mr. Peters: Well, you know you don't agree on certain things and then if you don't agree on it, why don't we do it this way and the next person says that way, well, you compromise. That's what you have to do.

The Campbells view their roles and responsibilities in marriage as old fashioned, Victorian style.

Mr. Campbell: Well, we were real old-fashioned, Victoria style. (Mary) did everything in the house, and I did everything outside. And I did the vegetables and (Mary) did the flowers.

Victorian values, considered traditional marriage values, are explained by Mr. Campbell as a social system of positive interaction, a give and take in responsibilities around the home. Marriage was seen as a life-long working partnership, where most women seemed content and satisfied with their roles of wives and mothers. They saw marriage as emotionally satisfying, and even emancipating. It was considered normal for a man to turn his entire paycheck over to his wife, whose job it was to determine spending for the family. Victorian attitudes were enacted in the Campbells marriage. Mr. Campbell commented that he was grateful for his wife's ability to conduct herself positively in social situations. "*She was always very congenial with people and she accompanied me on professional trips.*" He commented that there had never been a divorced member on the professional board he was involved with. It was assumed that if

a man could not get along with his wife, he would not get along with other board members. The Campbells' public relationship prior to dementia could be described as healthy. The couple wanted to present themselves as unified with a social responsibility, and presented that responsibility to the public with unity and grace even with the advent of dementia.

The Martins assumed traditional roles and responsibilities in the early and middle years of marriage:

Mr. Martin. When we yeah, it was when we got married, she, soon after she then started to stay home because the children were basically her responsibility as well as mine, but mothers according to the European style, mothers are more important than fathers, though fathers are very important.

The couples created a partnership in marriage, with a commitment to *stay together through thick and thin*, as well as connectedness in the early and middle years. There was a great similarity among couples in that they shared a loving relationship and responsibility for home and family. The factors that influenced marital satisfaction for the couples were doing things together, working through difficulties, and reciprocity. In the later years, each couple's shared experiences would call for renegotiations of roles and responsibilities when one spouse became ill. As Sharlin, Kaslow, and Hammerschmidt (2000) suggest a couple's shared history is particularly important for love in the later phases of life, when emotions both positive and negative, tend to become more intense.

Summary

This chapter introduced the six study couples: the Campbells, the Burns, the Gladstones, the Martins, the Smiths, and the Peters, and described the analysis and findings of the couples' meaning of commitment to the marriage relationship within their

social and cultural context. To the study couples, commitment in marriage meant you stay together for better or worse, richer or poorer, in sickness and in health, till death. Commitment was enacted in the marriage relationship by doing things together, overcoming difficulties, and reciprocity. A couple's experiences of getting settled into married life meant tough times and hard work in the early years. All couples successfully made the transition to parenthood during the early years of marriage, acknowledging the importance of positive family values, beliefs, and attitudes towards marriage passed on through their family histories. During the middle years of marriage, these couples were busy raising and launching children, enjoying family, friendships and travel, as well as experiencing the security of employment and a home.

Chapter Six

Findings and Discussion: The meaning of a diagnosis of Alzheimer's dementia within the marriage relationship

Introduction

In the later years of their marriages, the study couples experienced a challenge to their relationships unlike any experience they had in the past. One of each of the spouses was diagnosed with dementia of the Alzheimer's type in the early stages. A diagnosis of Alzheimer's dementia has a major impact on a marriage relationship. The spouse diagnosed was now considered a patient with a disease. Their spouse was now positioned in the caregiver role. In this chapter I analyse each couple's response to the experience and meaning of early-stage dementia to their marriage relationship through the three phases of the transitional process: pre-diagnosis, diagnosis and post-diagnosis.

In the pre-diagnosis stage, the meaning and experience of changes related to dementia and the marriage relationship will be explored under the narrative theme of 'awareness of dementia.... *noticing changes.*' In the diagnostic stage the experience of receiving a diagnosis and the impact of that diagnosis to the couple will be explored under the narrative themes of 'seeking a diagnosis... *looking for answers*' and 'dementia in the family history...*recognizing the pattern.*' Lastly, I examine the meaning of a diagnosis of Alzheimer's dementia to the marriage relationship.

Pre-diagnosis

Awareness of dementia... "*noticing changes*"

"*Well we, you know, what happened, really happened, is that we started noticing that she was losing it. She was forgetting very quickly and it wasn't only me. The boys, I mean they noticed it too.*" (Mr. Peters)

People with dementia often have poor insight into symptoms or deficits resulting from early-stage dementia and are therefore not the first ones to notice changes in their functioning. The dimensions of loss or lack of insight in people with dementia has been investigated in detail from different perspectives (see Howorth & Saper, 2003; Robertson, Nordstrom & Wijk, 2007), with the conclusion that there is a loss of awareness or insight into changes resulting from dementia. Robertson, Nordstrom & Wijk (2007) have identified a helpful approach to understanding insight from a socio-psychological or interactionist perspective (with the interaction being between spouses). The theory behind this approach is called *Awareness Context Theory.* This theory can be used to better understand social interaction in Alzheimer's disease. The theory differentiates between four awareness contexts of which the person can be part. *Closed awareness context* refers to a situation where one participant of two in a social interaction knows about the fact "X", for example, the memory problem is a symptom of Alzheimer's disease, but takes care not to disclose this to the spouse. *Suspected awareness context* refers to an interaction context where both spouses know X, but pretend not to. *Mutual pretense awareness* refers to an interactional context where both partners know X, but pretend not to. In *open awareness context*, both spouses discuss X openly. Thus, awareness is considered to be the context of interaction between the spouses not a state of mind.

The six couples' early awareness of dementia was consistently expressed as noticing memory problems and discussed in *open awareness context*. The "classic" symptom pattern of Alzheimer's disease begins with memory loss for recent events (Alzheimer Association, 2007). Subtle changes to the spouse's behaviour were first "noticed" when routine tasks such as driving or cooking dinner became difficult. Mr. Martin explains, "*I noticed she would sometimes confront me, and say ... you did not tell me about such and such a thing. And I would say, I did, and I did honestly, I did.*" Analyzing these types of encounters from a symbolic interactionist perspective means the sudden entry of these experiences into the social lives of the couples disrupted the agreed exchange of symbols existing between couples (prior to a diagnosis of dementia) in the course of day-to-day social interaction. Consequently, spouses were unable to place themselves in the position of the 'generalized other, a standpoint essential if meaningful interaction is to ensue. As spouses were now unable to attach and agree to such an object, it prompted them to ask the question, "What is going on?" or "This could be serious." Up until this point, the significance of subtle small changes in behavior could be plausibly explained by normalizing the significance of the event. Mrs. Campbell and Mrs. Peters explained their own change in behaviour as a normal part of aging. This is a common explanation as complaints about poor memory function have been shown to increase with age, and individuals often attribute such symptoms to aging rather than disease (Hodgson, Cutler, 2003). Keady (1999) suggests in this situation the change in behaviour may be normalized but not entirely discounted. Over time, as the 'encounter' was repeated, increased in severity or frequency, or new 'encounters' occurred, it becomes increasingly difficult to normalize events, and spouses now suspect something quite serious is happening.

This suspicion that something serious was happening was acted upon by all couples as they sought out answers and advice from their family doctors. All six couples were eventually referred from by family physicians to the neurologist and director of a memory disorders clinic in Winnipeg, for diagnosis. The interface with professional staff at the memory clinic, and the provision of a diagnosis, marked a turning point, propelling each couple into a new phase of their relationship where one spouse would be the carer and assume a caregiving role that would last several years, and see their care for their spouse evolving into tending for physical needs, a task that most couples did not find difficult to imagine.

The Martins' story

Mr. Martin did not find it difficult to imagine a time when his wife might require more help with her physical needs. He assured me and his wife that he would do anything and everything he could to ensure that his wife was well taken care of for the rest of her life. Since Mr. Martin's narration of the story of how and when they began to notice changes with memory was close to the classical form of the structure of a story depicted by Labov (1972), I used this author's framework for analysis (refer to Chapter Three under the topic of "Story") to organize the couple's story about their struggle in marriage based on Mr. and Mrs. Martin's first person narration in their joint interview.

Abstract

Mr. Martin: I didn't see that there was something going on until we had our vacation in Australia. Now we were 24 hours together for three weeks.

J: And?

Orientation

Mr. Martin: And each one of us have always been sure we would have our itinerary so that you could get your stuff ready because we were on tour with other people, 30 or 40 other people. The bus would leave sometimes very early in the morning and so we had to have the luggage out so you could prepare it in the evening and things like this, and she would then argue with me, and you know it became very strange to me. I said something's going on.

Complicating actions

Mr. Martin: Then we were in Darwin, the northern part of Australia and we're on a camel ride in the desert and we come back, take a shower, go to the restaurant and we were sitting around, a whole group of us were sitting around the table and talking about the events of that day and would finally look at me, yeah and you 'didn't take me along' was her comment. I said you were there. No, I wasn't there! So she became a little frustrated for that and you know, the other people sort of looked at each other and said, 'yeah, you were there.' Well, she was not convinced till we went upstairs and she confronted me with that again and so I said, 'This is the time to show some love and patience.' She was sitting on the bed and I took her hand and we knelt down and I looked her in the eyes, I says, 'You gotta believe me. Look in my eyes because there's something happening to you which it hurts me if that's what I think it is. It might, if that's what it is that you're losing your mind or something.' Well of course that was a major shock to her. So that's when I said, when we're coming back, she has to go through the tests. So for the next week it was very difficult for her, for me, because I had to remind her about things. She was very frustrated with herself. Yeah, actually we were coming back from our vacation. Immediately I started to look for answers. That means I phoned some of my doctor friends that we went right away to her doctor, made an appointment and they said, well, she had a thyroid problem. Maybe the medicine is too weak or too strong. Yes, she had cancer but that should not affect her brain. Yes, she had an operation of, you know, and she was on I think, estrogen, right, and there was some comments that estrogen had a devastating effect on some women. And they were getting cancer. Some it affected their mind as well. So we had a lot of questions. A lot of concerns...

Resolution

Mr. Martin: So we started pushing very hard and it took two years, two years finally, to actually get to someone that maybe had a kind of inkling, saying yes, you're going through the dementia stage into maybe the early stages of Alzheimer's. So we were finally connected with Dr. but we also had to find out, you know, there's very little help. There's very little research done. There is not enough medicine out there. There is not much help expected. So however, we went, we did research ourselves and then I found out about Mementin which was used already in Europe for ten years. It's not a curing but it's slowing the deterioration. It's slowing down the deterioration. Then I think that was not approved here in Canada here at that stage so it was then another, another medicine that we were able to get from him. But later it was Mementin was approved and he said,

take the combination. They're not working against each other. They're complementing each other.

Coda

Mr. Martin: And so, but I think it may have stabilized, but it has, I think, the last time we had her tested, they basically said there's a small deterioration taking place.

The level of stress couples experience in seeking a formal (medical) confirmation of events should not be underestimated. For many, like the Martins the period surrounding diagnosis is an important and often traumatic one. The struggle to get to a diagnosis is often complicated when other health related issues such as thyroid problems are involved. An accurate diagnosis is a process of elimination of other causes. Reaching the point of diagnosis was a relief for Mr. Martin as it validated his concerns and put the future into some form of context. Although a diagnosis of Alzheimer's disease can affect different people in different ways, the most common symptom pattern begins with gradual difficulty remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals also experience confusion, disorganized thinking, impaired judgment, trouble expressing themselves, and disorientation. Long-term memory often remains intact.
During the interview process, Mrs. Martin became very frustrated at not being able to express her feelings. She had difficulty finding the words she wanted to use as expressed in the following response:

J: Do you feel this?

Mrs. Martin: I feel it. I don't know how exactly they look at it. I find that I always have to, I have to come to a point so that I can verbalize properly. Just like this, you know, it's gone, you know, and...

J: Okay, so how do you manage? What little techniques do you have to manage on a day-to-day basis, would you say? Do you write things down?

Mrs. Martin: I have written a lot of things down, and it became too, it became almost, what the heck am I doing? It's not getting any better.

Mr. Martin: Well, we encourage her to read, when possible. We always keep a conversation going just to keep her mind active. In the morning, we usually have our newspaper. We go through the newspaper. We read the newspaper, have a discussion. Sometimes when I come home I say, 'Oh what did you watch?' Today is a typical day. It's Monday, and that's a laundry day. But we had to do a couple of chores in the morning so we did it together and then I sort of say, okay, we're going to bring my car in for a tune up. We have to go to the bank and I'll write it down for that day, and then you do the laundry. So we cross out the other day before because then all she needs to do is focus on that day. And that's what she does. She took the laundry down. She washed it. She ironed it. She wanted to watch Oprah, I guess, and took the wrong switch. She phoned me, I couldn't understand what the problem was, so I couldn't help her. So that's when I say, 'Okay take out the shrimps, I coming home early, and so you can still see Oprah.' But it's not the most important. So we do work out a routine. And as always like to be together and it is now that she finds it more important to be with me.

Mr. Martin's narrative account was a vivid representation of "taking on" the caregiving role. The task of caregiving is not assumed all at once. As was the case with Mr. Martin, he had the opportunity to grow into the role, taking on responsibilities gradually. The symptoms and behaviours of early Alzheimer's required that Mr. Martin start monitoring his wife's activities, in other words, take on a supervisory role. When analyzing Mr. Martin's response to his wife's daily struggles, I am reminded about the power of the past to help understand the present. This couple had a long history of a loving, close relationship and always enjoyed doing things together as they stated often throughout the interview. They cared for each other during difficult times and although this was a "different challenge" as Mr. Martin explained, the true test of commitment in marriage was how you care for each other.

The Peters' story

During the interview Mrs. Peters talked about always having a poor memory.

"Maybe I was always dumb, I don't know. (Laughing) I don't know if I had such a good memory cause I couldn't memorize for concerts at school and then I didn't want to take part in them cause I could not memorize."

Mrs. Peters is aware of her ongoing problems with memory and was able to express her concern that it had been a lifelong embarrassing issue.

This comment was interesting to me. I recalled when working as a clinical social worker at a memory assessment clinic that patients diagnosed with Alzheimer's disease often reported a history of poor memory all of their lives. In fact, the dementia specialists I worked with asked the question – "*Have your problems with memory changed over the years*?" For some the answer would be, "*Yes, I always had an excellent memory"*, while for others, like Mrs. Peters, it would be, "*No, I always had memory problems.*" Research into problems with memory early on in life as a condition that predisposes people to Alzheimer's disease has some validity. Some tests of memory, problem solving, attention, counting, and language skills can identify people with higher risk of developing Alzheimer's disease.

Mr. Peters described what "really happened" to his wife's memory prior to a diagnosis of Alzheimer's disease.

Mr. Peters: Well we, you know, what happened, what really happened, is that we started noticing that she was losing it. She was forgetting very quickly and it wasn't only me. The boys, I mean they noticed too.

J: So what kind of things did you notice first of all?

Mr. Peters: Well, a lot of repetition, you know, and she would misplace things. she was looking for things, eh, and that's where it started, and if they couldn't remember things, you know...

J: What did you think at the time?

Mr. Peters: Well, we knew something was going on, and that's why the doctor was informed.

I asked Mrs. Peters to respond to gain more of an insider's perspective.

J: Did you notice changes yourself?

Mrs. Peters: Well, I thought I was taking after Mom. Mom was very forgetful.

Mr. Peters: But at that point in time, I don't think she really realized what happened. I know my sister Betty stayed with us on a weekend there one time, and she noticed that too that she wasn't as sharp. Working in the kitchen, where did I place this? Where did I place that? You know...I honestly think people with dementia, they try to cover up to a certain extent.

J: Do you think that was the case?

Mr. Peters: Yeah, I think they do. I think they try and hide it, and she doesn't, not compared to her sister. She's very open. She'll talk to anybody about her memory loss, eh?

Mrs. Peters: I tell them. If it's a friend, I say, if you see I'm doing something stupid, I said, just stop me because I says, I talk, like you know, and I'll be doing something and then I realize, oh what am I doing this for. See I knew it myself, so I can do that. Like with the family, I don't, I feel bad. I'm making a big meal, and did I put this in there? You know, just salt or something like that. There I have to put my finger on something on a spoon to see.

Looking back, Mr. Peters could see that his wife's dementia started years before a diagnosis. This period is often referred to as the "invisible stage" and it is suggested that only the individuals concerned suspect something is wrong. Mrs. Peters describes it as *doing stupid things*. Doing stupid things such as misplacing important items, and loosing short term memory increased causing major concern for the family. Since dementia takes many forms even in the early stages, it was hard to know if Mrs. Peters behaviours were significant enough to warrant concern. It wasn't until her behaviours interfered with normal life, until they interfered with her functioning, such as her ability to safely make meals, that they were deemed indicators of Alzheimer's disease. Mrs. Peters described to

me how she was always shy and preferred staying at home to socializing. Her personality appeared to have changed, another sign of dementia. She was very engaging and dominated much of the conversation during the interview. She had important insight into her dementia experience and the meaning it held for her. Unlike many individuals with Alzheimer's disease she could explain her situation to friends. It is my belief she did not feel stigmatized, but sad by her situation.

Another important point Mrs. Peters raised was that she thought she was taking after her mother who was very forgetful. Family history of dementia was a theme common to all the couples except for Mr. Gladstone who lost contact with his parents early on and did not know who his relatives were. Family history and increasing age are the primary risk factors for Alzheimer's disease.

The Campbells' story

"*How many children do we have (Dave)*?" (Mrs. Campbell)

I was clued into some of the deficits Mrs. Campbell experienced during the first home visit at the time the couple were filling out the questionnaires. Mrs. Campbell struggled with her memory to try to find the answer to the question: *How many children do you have?* After much deliberation and memory searching, she finally decided to ask her husband who politely gave her the answer. The progress of dementia of the Alzheimer's type is described as slow and insidious. Mrs. Campbell experienced that progress. Contrary behaviour such as remembering the number of children you have is a serious sign that describes behavior of a loved one inconsistent with the normal expectations of the caregiver. As a result of the Campbells' long-term relationship they knew each other very well and had developed expectations about how each other should

behave. In the following Mr. Campbell talked about a critical event that helped "sort out" and "crystallize" what was going on. This event immediately propelled him to seek help:

J: Who received the diagnosis of dementia and how did it happen?

Mrs. Campbell: Well, we just began to realize that if I took messages on the phone, if I didn't write down what I was told, you know, come to dinner on Friday night, and then put it on the calendar...

Mr. Campbell: Well, I think the most dramatic one, (Mary), was you were running all – Mary ran our social life cause I was very busy at the hospital, and she did all the party planning and things like that. Well the children had all left home by this time, but she arranged to go out to a luncheon with a friend. The friend came to pick her up. (Mary) had no idea why this friend had come. So this lady, her husband was a doctor, and I worked at the University, and we quickly sorted things out. It was obvious by some lost items and things like that and this crystallized and that in turn led to a referral to Dr. (X) who had been doing a lot of research in the field.

I asked Mrs. Campbell how she felt when the doctor told her the diagnosis and she responded:

Mrs. Campbell: Well it made me realize that I'm getting old, and he said, 'How do you remember things you're suppose to do?' And I said, 'Well, I'm left handed, so I pick up the phone with my right hand and I have a paper right there and with my left hand, if someone wants me to usher, usher for church, or bring cookies to University Women's Club or whatever, I write it down and if he hears me making arrangements, he comes out and makes sure it gets on the blackboard.'

Mrs. Campbell, like many other older Canadians believes that as people grow older, their mental capacities decline, and that is part of normal aging. She is not aware of the impact her memory loss has on her interaction in the marriage relationship. A current popular cultural remark, meant to be funny, when an older individual is at a loss for a word or a name is, "I'm having a senior moment." Even though Mrs. Campbell was aware of changes in her memory her reaction was a lack of concern and insight into the significance of the diagnosis. From a neurobiological perspective, Mrs. Campbell would be described as having 'anosognosia', that is, impaired ability to recognize the presence

of, and appreciate the severity of, deficits. From a psychological perspective, the lack of insight results from a threat to self and a coping response. Robertson, Nordstrom & Wijk, (2007) offer a less developed socio-psychological or interactionist perspective. Here, the awareness is not considered to be a state of mind, but the context of interaction between two or more people. "The socio-psychological approach, although less developed than the neuropsychological and psychological approaches, contain a badly needed understanding of the importance of social context in influencing and constructing the opinion of oneself and the disease" (p.56).

The Burns' story

Mrs. Burns noticed "early warnings" prior to her husband being diagnosed with Alzheimer's disease as she relates in the following:

Mrs. Burns: I noticed that he was losing memory and that he was forgetting things, and basically, (Sam) did, like after he retired, he worked for, or did a lot of work for Harvest. He was also chairman of the board of a foundation and those things required a lot of paperwork and a lot of dates and a lot of memory, and then I noticed he was starting to get confused, having trouble with it...and having trouble with the taxes at the end of the year, you know, figuring out which went where and I knew that was the (Sam) that has always been so on top of everything...this was three years ago, when it started, and so mentioned it to our family physician, and he immediately made an appointment with Dr. (X) to test things.

I asked Mr. Burns if his memory problems caused him any difficulties:

Mr. Burns: Yeah, I think so. My memory isn't what it used to be. I have to write everything down. She keeps me abreast, oh today we have to go here or tomorrow we have to do this. But I keep active. I think that is important. We walk a lot.

Actually, Mrs. Burns responded "*We do*?" and he corrected his statement to "*Oh we used to.*" Fabricating stories is a common response to a question where temporality can be misinterpreted. The psychiatric definition of fabrication is *a plausible but imagined memory that fills in gaps in what is remembered.* My experience with

fabrication has been that individuals with early dementia want to preserve their self-esteem and often answer a question with a response that protects their dignity and self-determination. Mr. Burns wanted me to like him. And I did.

Mrs. Burns talks about the frustration experience when her husband would repeatedly ask the same question, "*What are you doing*?" "*I'll tell him, and then 3 minutes later, What are you doing*?" Frustration has a negative impact on caregivers' day-to-day interactions with their spouses and, with a build-up, can lead to caregiver stress.

The Gladstones' story

In my journal notes of the first home visit to the Gladstones, I noted the couple related to each other in a kind and loving way half of the time and at the other times Mrs. Gladstone tended to challenge her husband's memory, past and present. Mr. Gladstone was quiet and withdrawn, while Mrs. Gladstone was enthusiastic, dramatic, and talkative. Their home had the feeling of being well lived in, comfortable, warm, with lots of outdoor plants and flowers, and birds enjoying their birdbath and birdfeeders.

In my journal notes of the second home visit, and on my arrival to the front door, Mrs. Gladstone anxiously whispered that her husband was put on a sedative after an angry outburst regarding the purchase of a new TV. The 20 year old TV was no longer working and their son was going to purchase a new TV. Mr. Gladstone wanted it fixed. The argument lasted one hour. Mrs. Gladstone told me she was not able to reason with him. "He is calmer now," she reported, "things are better." During the interview, Mr. Gladstone made several derogatory comments about himself such as, "My wife deserved better than me." The couple's relationship appeared "sparky." Mr. Gladstone would take

the opposite position to his wife and hold firm. Mrs. Gladstone expressed resentment over decisions made over the years particularly when it came to moving.

I was alerted to Mrs. Gladstones concern for her husband's memory loss early on, with the first question I asked, which was to tell me when they met and married - their wedding story. Immediately, Mrs. Gladstone told me that her husband had a terrible memory even prior to Alzheimer's:

Mrs. Gladstone: I should say that (Peter) has always had a terrible, terrible memory. So if I do most of the talking, it's cause I know he won't remember anyway. I mean nothing to do with Alzheimer's.

Mr. Gladstone surprised her when he said, "*We got married in 1950, wasn't it*? She replied "*Oh! Yes.*" He then went on to give the exact date. His wife's response was, "*Good God!*" She was obviously very surprised he remembered their wedding date. When I asked them to recall changes in memory or behaviour, the response was as follows:

Mrs. Gladstone: It was just so gradual that one day something went 'ping' and they all sort of began to come together, and my daughter is very observant as well. I think my daughter gave me a nudge, you know, and I began to put things together a bit. You had a fall, didn't you, and you went to your GP.

Mr. Gladstone: Had a what?

Mrs. Gladstone: You fell, tripped.

Mr. Gladstone: When?

Mrs. Gladstone: Oh, I don't know, Darling, a year, a year and a half ago, something like that.

Mr. Gladstone: Yeah, yeah. I did, yes. But that's what affected my memory.

Mrs. Gladstone: I don't think it affected your mind. It's called Alzheimer's Dear.

Mr. Gladstone: I can't remember honestly why I went to see him, or why I went to see him.

Mrs. Gladstone: I've honestly been putting two and two together and making five. Then, I think things sort of began to click together in my head, listening to the questions the GP was asking...he was getting a very simple test, which I now know were pretty standard.

J: Okay, for memory issues?

Mrs. Gladstone: Yeah. And then I think he referred you to Dr. (X).

Mr. Gladstone's angry outburst over the purchase of a new TV resulted to some degree from the impact of neurological changes in the brain, the mechanism by which behavioural and psychological symptoms of dementia occur in Alzheimer's disease. The mechanism creates increasing loss of brain functioning that affects cognition, emotions, and functional capacity. One way of explaining this mechanism, suggest Mittleman, Epstein & Pierchala, and thus Mr. Gladstone's behaviour, is based on the theory of progressively lowered stress threshold (PLST). This theory posits that a person with impaired cognition is particularly susceptible to influences from the environment. Mr. Gladstone found it difficult to adjust to new situations and complex tasks and found it difficult to articulate what was disturbing him. He therefore would respond with irritability, agitation, aggression, withdrawal or depression. Depression is common in individuals diagnosed with Alzheimer's disease and Mr. Gladstone claimed to be depresses. Another explanation for the events around the TV from an interaction perspective could directly result from the response from Mrs. Gladstone. She was not able to take the role of her husband in this situation and recognize his frustration. As she argued with her husband he became more and more upset.

Mrs. Gladstone raised an interesting point when she said her daughter observed what was going on and gave her a "nudge" to seek a medical opinion. Krull (2005) suggests *outsiders'* observations are important because they point out something about the cared for person that makes caregivers re-examine their definition of the situation. In

the Gladstones' situation, their daughter was able to point out her father's behaviour she considered outside of the normal range for him. Mrs. Gladstone then realized something serious was occurring.

The Smiths' story

The Smiths described themselves as a couple who were partners, always there for each other, but Mr. Smith commented, when dementia drifted in, "*it changes your whole life*." Here the couple's respond to their experience of the awareness of dementia:

J: When did things start changing with your memory?

Mrs. Smith: You know, I can't answer that.

Mr. Smith: They asked me that at Dr. (X) office.

J: Was it sort of slow?

Mr. Smith: Oh yeah. I never noticed it coming.

J: What kind of things did you eventually notice?

Mr. Smith: Forgetfulness was one of the big things... What used to be at the snap of her fingers, now she couldn't come up with. And it's got worse. Hopefully with this new drug coming out now, but according to our family doctor, I went to see him before we went in to, you know, I wanted to, because I didn't understand. So he told me, he says, it's a good thing to do. If there's an increase in memory from 10-15%, it's worth it. So that's basically what we're looking for.

Mr. Smith: Like I say, it was little things.

J: For example?

Mr. Smith: It's hard to say because like I say it came on gradually and that would be probably if she had gone to get groceries and I would say, 'Did you get some of whatever'... 'No, I forgot.' So, I, you can forget, I forget, you forget. Everybody, so like I say, where do you draw the line and say, this is when it happened? You can't.

Again, the Smiths remind us of the slow and insidious nature of the onset of dementia. Mr. Smith recognized his wife's dementia symptoms were progressing. They

both held out high hope for an increase in memory with the new drug she was taking. Cholinesterase inhibitors (e.g. donepezil [Aricept], galantimins [Reminyl], and rivistigmine [Exelon] are currently the drugs most commonly prescribed to treat symptoms of dementia. However, the Smiths and four other research participants were involved in the start-up of a new clinical drug trial.

Diagnosis

Seeking a diagnosis... *"looking for answers"*

"Yeah, actually we were coming back from vacation. Immediately I started to look for answers. That means I phoned some of my doctor friends. Then we went right away to her doctor." (Mr. Martin)

A symbolic interactionist framework is a useful perspective to understand the process of seeking a diagnosis of Alzheimer's disease as Mr. Martin did. The emphasis is on the meaning that individuals ascribe to particular interactions and how those meanings alter the interpretation of experiences. According to this framework, it is not objective events that result in seeking a diagnosis; rather it is the interpretation of events that is important. The awareness of unusual behaviour by the partners in this study caused the spouses to examine and account for the changes. After making attempts to adapt, the spouses concluded something serious was going on and help must be sought.

The general practitioner (GP) is often the first physician to see and assess patients with possible dementia because families first turn to them for answers. With the current focus on the benefits of an early diagnosis of 'early dementia'[10] the GP will often refer

[10] For example, the cut-off for mild dementia on the commonly used Mini Mental State Examination (MMSE; Folstein et al., 1975) varies from 17-23 (Richards, Monitz-Cook, Duggan, Carr & Wang, 2003).

their patient to a specialized memory clinic where there is possibly a better chance of diagnostic certainty [with the use of specialized staff and tests].

All couples I interviewed were optimistic regarding medication use. Their optimism is supported in a recent research project on the subject (Lindstrom, Smyth, Sami, Dawson, Patterson, Bonic, Post, Barber, Ollerton, Singer, & Whitehouse, 2006). They hoped that the use of medication would stabilize the symptoms of the Alzheimer's person they were caring for and prevent further decline. The research also indicated that persons mildly to moderately affected by dementia are capable of verbally expressing their opinions in the context of research-driven focus groups. I also found participants with dementia able to express their opinions in the context of joint interviewing with their spouses concerning their marriage relationships and the dementia experiences.

In the context of joint interviewing, the couples often talked about understanding and becoming aware of the dementia experience from personal experience with a parent, grandparent, or relative. Recognizing a pattern of dementia in the family history became a recurring theme.

Dementia in the family history... *"recognizing the pattern"*

Mr. Campbell talked about recognizing the pattern of dementia from his personal experience of caring for his mother, as he describes:

Mr. Campbell: Well my mother had the same problem so we had seen the pattern. She was living and my father died. He had a stroke and lived quite long, about 2 years, and every day she went out to see him, even though he couldn't communicate. But she did her duty and then she had to live alone for awhile, then her memory began to fail. So we brought her out here to see if we could put her in an institution nearby or she could live here but she wouldn't have any of it. But I've learned a great deal about it from her.

Mr. Campbell started to recognize a pattern of dementia as his wife's symptoms became progressively worse – he had seen this pattern in his mother. Mrs. Peters also had seen the pattern of dementia in her family history. Both of her mother mother's sisters and her own sister had dementia symptoms. She recognized that she was going down the same path as she explains:

Mrs. Peters: My mom was bad, very bad, and I know her sisters were, and then I thought, oh I'm going down the same path.

Mr. Peters: Well, your sister was already on medication for dementia when you found out.

Mrs. Peters: I have a feeling she wasn't as bad as me, like when she started to do it.

Mrs. Peters experiences her dementia as bad. Because the onset of her symptoms started when she was in her 60s she would be considered to have early-onset dementia (age<65). The younger age of onset of Alzheimer's disease, the more likely that there are genetic factors, such as apolipoprotein (APOE) E4 allele[11]; the older the age of onset of Alzheimer's disease, the more likely there are environmental or medical risk factors involved (McMurtay, Ringman, Chao, Licht, Saul & Mendez, 2006, p. 598).

I asked the Burns if there was a family history of memory problems. Mrs. Burns recalls that her husband's grandfather had memory problems:

J: Any family history of memory problems?

Mrs. Burns: I think your grandfather, did he not? Well I know he used to wander out of the nursing home and didn't know, like they had to watch him, so grandfather I think had that history, but I can see it in my mother, more of a dementia. Series of small stroke, that's what it was anyway, whereas with (Sam) there was no sign of stroke. So I did recognize the problem.

[11] It is interesting to note that APOE- E4 does not confer increased risk for Alzheimer's disease among African Americans or Hispanics (Kane, Ouslander, & Abrass, 1999).

Mrs. Burns is correct in her analysis. There is a difference between dementia caused by stroke and dementia caused by Alzheimer's disease. Vascular dementia is predominantly due to multiple infarcts (multi-infarct dementia) or small strokes, and accounts for about 15 percent of all dementia in the geriatric population (Kane, Ouslander, & Abrass, 1999). Instead of a slow insidious onset characterized by Alzheimer's disease, there is a step-wise deterioration pattern. Each small stroke can create a progression of the dementia.

Mrs. Smith recalled that her sister had had bad memory problems:

J: Was there anybody in your family, anybody, your grandparents, parents, that had memory problems at all?

Mrs. Smith: My sister...she was really bad. She passed away now.

Mr. Smith: Finally had to put her in a home because nobody could handle her.

Mrs. Smith: They couldn't leave her by herself.

Mr. Smith: After living alone, hardest of all for her. Like I said, she put up her Christmas tree and she'd take it down in March hoping her grandchildren would come to visit. They lived in Neepawa. They wouldn't come. They never came. But they were there when she passed away.

Mr. Smith raised an interesting point when he commented that the grandchildren never visited. It is not uncommon for family, especially children, to "not visit" their parents diagnosed with dementia and who are living in a personal care home setting. My experience in working in a personal care home is that people with dementia know when family visit. They may not be able to communicate in the traditional ways, but they feel the presence of their loved ones.

Post-diagnosis

"*It's called Alzheimer's Dear.*" (Mrs. Gladstone)

Formalization of the caregiver and patient role

Receiving a diagnosis of Alzheimer type dementia was considered a "critical juncture" in the marriage relationship of the six couples. Although they were suspicious, the diagnosis formalized the caregiver role of the undiagnosed spouse. From a structural perspective, the couples' stories of noticing progressive changes and becoming aware of dementia (sequence of events) would be consistent with the *complicated action* element of the narrative. The *evaluation* element would be considered the significance of changes in behaviour of the spouse, and how the spouse, telling of the changes, wanted to be understood. For example, Mr. Martin wanted me to understand his character as a man of integrity, and Mr. Campbell as a morally obligated spouse. The *resolution* element would be considered seeking a diagnosis. The plot of the six couples' romance stories was *development through struggle and victory.* The couples' commitment to their marriages meant they always did things together, they worked through difficulties, and they believed in reciprocity in their roles and responsibilities in marriage.

The couples were not relieved to finally receive the diagnoses. They had all had long histories of significant events experienced together. They had become aware of progressive symptoms for approximately one to two years prior to the diagnosis. They were also aware of the dementia pattern from their own experiences and memories of caring for parents or relatives. Mr. Smith recalls the news of the diagnosis: "*Well, I certainly wasn't happy, but what are you going to do? That's life, eh? It changes your whole life.*" Receiving a diagnosis of Alzheimer dementia is distressing, particularly to

the spouse who will now be expected to be the caregiver as Mrs. Gladstone reports: "*Well, it's different now because I have to be much more of a caregiver, keep half an eye on what's going on, where he is, you know, does he need a nap or...?*" To Mrs. Martin, a diagnosis of Alzheimer dementia meant losing her sense of self as she explains: "*I feel it. I don't know exactly how they look at it. I find that I always have to, I have to come to a point so that I can verbalize properly. Just like this, you know it's gone, you know and...*" Adjusting to loss, particularly loss of self, is considered an overarching theme as a psychological reaction to a diagnosis of dementia in couples To Mr. Smith and Mr. Martin, a diagnosis meant *everything changes*. This means couples recognize current difficulties and losses, but have also developed coping strategies and demonstrate resilience in the face of difficulty.

Summary

This chapter has described the analyses and findings of the couples' responses to the experience and meaning of early-stage dementia to their marriage relationships through three phases of the transitional process: pre-diagnosis, diagnosis and post-diagnosis. It is during the pre-diagnosis phase that couples gradually became aware of memory problems that were advancing with time. Initially they passed off memory problems as part of normal aging, but in time, all the couples started noticing other signs of deterioration, such as difficulty with daily tasks such as cooking, banking, and driving. This behaviour forced them to look for answers and seek the advice of their doctor. Becoming aware that something was wrong produced frustration, uncertainty, and fear within the marriage relationship. Friends and family noticed changes in behaviour and expressed their concerns. In some cases family members initiated the stage of sharing

awareness. Spouses with dementia were not often able to communicate their problems to family or denied there were any problems.

During the diagnostic phase, these couples all sought help and eventually received a diagnosis of Alzheimer's disease from a neurologist specializing in the area of diagnosis of memory disorders. Couple's felt validated in knowing what was going on, but not relief from the concern for future losses. Spouses unaware of their memory problems were forced to acknowledge their self-image no longer matched reality.

During the post-diagnostic phase, couples managed to move on with life in spite of dementia. They accepted the prospect of living with dementia. Many couples recognized the pattern of dementia from their family history. They understood changes in the roles and responsibilities in their marriage relationships would continue. They believed that marriage commitment would be uninterrupted in the transition process. The spouse diagnosed with dementia expressed fear of being a burden, dependent, or in the way. The spouses now designated as caregivers were determined to hang in for as long as possible in that role. Couples struggled to integrate dementia into everyday life.

Chapter Seven

Findings and Discussion: Reappraising and reconstructing meaning through changes in the marriage relationship after a diagnosis of dementia

Introduction

During the post-diagnostic phase, couples managed to move on with life in spite of a diagnosis of Alzheimer's type dementia. They understood changes in the roles and responsibilities in their marriage relationships would continue through the progress of the disease. In this chapter, couples reflected on how they reappraised and reconstructed the meaning of those changes to their marriage relationship as they integrated dementia into everyday life.

The first section of the chapter describes the couples' marriage satisfaction and gender role orientation in relation to their DAS and ROR scores. I also comment on couples' responses to the commitment to marriage questions. The second section is my analysis of understanding the caring relationship and the sub-theme, 'being there for each other'. The third section explains changing roles and responsibilities, focusing on the sub-themes of 'dependency and loss'. The fourth section focuses on changing relationships and the sub-theme 'drifting away'. The fifth section examines future plans and the sub-theme 'living day-to-day.'

Integrating dementia into every-day life

Integrating dementia into every-day life following the diagnosis of Alzheimer's meant couples would continue to adjust to subtle changes and threats, both in their

personal relationship and in their roles and responsibilities as a married couple. Insight into effects of dementia on changes in the marriage relationship was gleaned from the marriage satisfaction questionnaires couples filed out at the initial home visit. The DAS (Dyadic Adjustment Scale) is a subjective rating of the couple relationship. It was designed for an overall assessment of dyadic adjustment as well as for measuring the following four dimensions:

1. *Dyadic consensus*: the degree to which the couple agrees on matters of importance to the relationship;
2. *Dyadic satisfaction*: the degree to which the partners are satisfied with the present state of the relationship and are committed to its continuance;
3. *Dyadic cohesion*: the degree to which the couple engages in activities together;
4. *Affective expression*: the extent of agreement regarding demonstration of affection and sexual relations.

The concept of satisfaction refers to the degree of satisfaction based on fulfillment of expectations. The concept of marital quality or marital adjustment is considered more global. Given the continuum of possible scores, a fixed cutoff point is recommended. However, under the circumstances of couples filling out the questionnaire after one spouse was diagnosed with Alzheimer disease, I chose to provide an overall mean score as well as individual scores. The DAS questionnaire is Appendix E page 328 and the ROR questionnaire is Appendix F page 331.

Describing a couple's marriage satisfaction and gender role orientation in relation to DAS and ROR results

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DAS results:

*The DAS mean score for a married population considered satisfied is **114.8/151**
*The DAS mean score for the study was **119.8/151**

H represents husband and **W** represents wife

Scores:
Gladstones (H:81, W:92)
Burns (H:124, W:112)
Peters (H:123, W:117
Martins (Together: 120)
Smiths (Together: 140)
Campbells (H: 143, W:126)

ROR results:
The ROR mean score of 12/25 suggests mid-range between traditional and egalitarian role orientation (traditional refers to male breadwinner and female homemaker, and egalitarian refers to an equality role orientation in marriage)

Scores:

Burns (H: 12, W:8)
Campbells (H:10, W:12)
Peters (H:11, W:11)
Martins (Together: 12)
Smiths (Together: 12)
Gladstones (H:11, W:20)

Figure 9: The distribution of the couples' responses to DAS and ROR scores

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Figure 9 illustrates the couples' DAS and ROR scores. The total scores on the DAS fell between 81 and 143. The mean score for Spanier's normative married population who are satisfied is reported to be 114.8. The group classified as *satisfied* reflect the average dyadic adjustment. According to Spanier (1976) then, the Burns, the

reflect the average dyadic adjustment. According to Spanier (1976) then, the Burns, the Peters, the Martins, the Smiths and the Campbells would be classified as satisfied (*dyadic satisfaction*) and adjusted. The Gladstones' DAS fell below 96 and would be considered mid-range on satisfaction and adjustment, meaning their relationship was not deemed dissatisfied. This finding reflects the global theme of 'marriage is for life' found in the narrative texts of the couples. Together they represent global coherence connecting globally and thematically with the rest of the account making, a meaningful story (Agar & Hobbs, 1982). All couples, with the exception of the Gladstones, could be considered as having *dyadic cohesion,* reflected as well in the theme from their narrative texts 'doing things together,' and represents local coherence generated from the core narrative (Agar & Hobbs, 1982). The dimension of *affection expression* was most often not responded to in the same way by husband and wife or not answered. More specifically, I refer to the question asking if couples had differences of opinion or problems in the relationship with respect to Question 29, "being too tired for sex", and Question 30, "not showing love." Husband and wife scores on the DAS were similar. This response represents *dyadic consensus*. The exception was the Campbells. A lack of similarity in this situation can be explained by the fact that Mrs. Campbell was confused in answering some of the questions. This confusion was also experienced by Mrs. Martin and Mrs. Smith. All couples responded by answering the questionnaires together, deciding between them the correct answer.

Although for the most part the couples' scores suggested they were satisfied and adjusted in their marriage relationship, the response to one question stands out:

(31). The dots on the following line represent different degrees of happiness in your relationship. The point, "happy" represents the degree of happiness of most relationships. Please circle the dot that best describes the degree of happiness, all things being considered, of your relationship.

- Extremely unhappy
- Fairly unhappy
- A little unhappy
- Happy
- Very happy
- Extremely happy
- Perfect

Although Mr. Campbell reported the highest adjustment score of 143, he circled the answer to the question as "*extremely unhappy*", his wife circled "*very happy.*" Mr. and Mrs. Martin, also with a high adjustment score, circled the answer to the question as "*fairly unhappy.*" Mrs. Gladstone circled "*a little unhappy'*, which was consistent with her narrative text. The Peters, Burns, and Smiths circled the answer "*very happy.*" It appears that dementia has less of a negative impact on marriage satisfaction and more of an impact on the degree of happiness a spouse experiences in marriage.

The ROR measures the marital partners' gender role orientations, which reflect their perceptions of marital and parental sex roles (Snyder, 1989). The pattern in Figure 8 suggests most couples' ROR scores are mid-range, around 12/25. This score would suggest an orientation between traditional and egalitarian. The exception was Mrs. Gladstone who scored 20/25, considered traditional. In her narrative text, I sensed Mrs. Gladstone's life-long struggle for independence in her marriage, and now that her husband had Alzheimer's disease, she was less independent than ever. An orientation between traditional and egalitarian is not a surprise to me. Several couples told me they learned about gender equality from their children and were often not sure what to answer

in the ROR, believing the questions were too "black and white" with no grey to check. In some cases, where the spouse was deliberating for some time, I suggested the spouse answer by marking a check in the middle, answering neither yes or no. This tended to satisfy the spouse, as they did want to answer all of the questions. Therefore, the scores reflected invalid answers.

Changes in marriage commitment over time

Couples were asked to fill in their answers to two questions based on Swensen and Trahaug (1985) Commitment to Marriage. The two questions were: (1) why did you marry your spouse? And (2) why have you stayed married to your spouse? The purpose of these questions was to assess change in commitment over the course of a marriage. The first question that asked couples why they married was considered to be the beginning of the couples' relationship. The second question that asked couples why they stayed married was considered to be the present time. The authors found that fewer marriage problems were experienced when the partners' commitment was based on valuing their spouse as a unique person rather than valuing marriage as an institution.

I chose not to rate the scores along a continuum as suggested by Swensen and Trahaug (1985) but, rather, to identify if changes to commitment had occurred over time. Most spouses of couples responded the same way to both questions, without hesitation. They married their husband/wife because they loved them; they stayed married to their husband/wife, basically, for the same reason. This consensus represented no change in valuing their spouse as a unique person with or without a diagnosis of Alzheimer's disease, an interesting finding. Mr. Campbell and Mr. Peters responded to the questions rated in the direction of valuing marriage as an institution as follows:

Q: Why did you marry your spouse?

Mr. Campbell: It was the natural thing to do, strong family tradition

Mr. Peters: Companionship

Q: Why did you stay married to your spouse?

Mr. Campbell: Everything fell into place, children became a priority, career very successful, family tradition of good marriages

Mr. Peters: Commitment to the wedding vows made to each other

Both Mr. Peters and Mr. Campbell were caring for spouses with Alzheimer's disease. Their commitment over time to the institution of marriage had not changed, again reinforcing the global theme of *you marry for life*.

Understanding the caring relationship... *"being there for each other"*

Changes in a couple's personal relationship after a diagnosis of Alzheimer's disease meant reappraising and reconstructing the caring aspect of their relationship. How couples cared for each and about each other prior to dementia provided a platform to understanding how couples negotiated their new caring relationship.

One of the questions couples were asked was how they cared for each other before and after a diagnosis of dementia. The meaning of caring, the exact nature of caregiving, and the dilemmas of the caring relationship are complex. Dalley (1988) suggests, for example, at the affective level, a distinction can be made between 'caring for' and 'caring about'. The first has to do with the task of tending another person; the second has to do with feelings for another person. According to Dalley (1988), the mixing of the caring functions (for and about) has implications for both parties in the

caring relationship. He suggests both find that the affective relationship of caring about each other becomes complicated by overlaying of the 'caring for' relationship. "Love, in the context, often becomes fractured or distorted by feelings of obligation, burden, and frustration (p. 10)."

The major theme of the couples' caring relationships pre-diagnosis was *'being there for each other'* during periods of illness. For the Campbells, being there for each other meant that Mr. Campbell would seek the advice/expertise of his physician colleagues at times when he or his wife would become seriously ill. He described having a casual attitude towards medical care, and not getting lathered up about things. Although he did not describe times when he directly cared for his wife, he cared about her as a committed morally obligated husband, the character he demonstrated throughout his stories of struggle and triumph. He talked of a rare time when he was ill, when he had a hernia operation. His wife was at the lake with their daughter and grandchildren when he phoned to let her know that he couldn't go down to the lake that following weekend. *"I'm in the hospital and I just had an operation" (Laughing).* His daughter took a taxi to the hospital and because she had a beginner's license, drove her father's car home. In the morning the daughter made his breakfast, went to work and put him out in the backyard, where according to Mr. Campbell *"I picked 12 liters of raspberries."*

Mr. Martin believed the true test of commitment is how couples care for each other. He described friends and acquaintances leaving their spouses when the wives were diagnosed with breast cancer. *"Now how more awful can one be?"* He told of the time when a woman left her husband when he was diagnosed with colon cancer. Mrs. Martin closed down her new garment boutique store after her diagnosis of colon cancer. Mr. Martin recalls:

Mr. Martin: "She was 50 when she closed that down. Yeah, it was shortly after you had cancer and that's 18 years ago. It could be before that time, during that time, yeah. She wanted to die at that time because her, she couldn't accept the fact that the colostomy would be part of her life...so it needed a lot of encouraging. We went to the cottage quite a bit and we were clinging together quite a bit, because I said, 'No, you don't give up. I need you and the family needs you. You're a strong person. You will pull through,' and she has done remarkably on that point. This is a different challenge." (Mr. Martin is referring to Alzheimer dementia as a different challenge)

Mr. Martin consistently characterized himself as a man of integrity throughout his stories of struggle and victory. This character was also evident in the way he cared for his wife during difficult times.

Mrs. Burns talked about the times her husband was there for her. She describes him as her "life saver," strong as an ox. He always looked after her during her cancer treatments, and it was a frightening time when her whole system stopped working. She was not able to walk or do anything and she stated, "*He looked after me there too.*" Mrs. Burns' character throughout her stories was one of a dedicated wife. Mr. Burns was a dedicated husband and cared for his wife with compassion and tenderness during difficult, the times when she was ill.

To Mrs. Smith "*it is the little things that make the big difference*" when caring for each other. When her husband was hospitalized, she would spend the day with him and not leave until visiting hours were over in the evening. She would cook him food and take the food up to him in the hospital. Mr. Smith would bring up take-out to his wife whenever she was hospitalized and also stay every day until visiting hours were over.

Mrs. Gladstone had several surgeries related to Crohn's disease. She believed she pretty much looked after herself during those times and other times of illness throughout the marriage. The Gladstones found the question about caring for each other prior to dementia difficult to answer. To some degree, couples like the Gladstones care for each

other throughout their lives. It is more or less a natural role in a marriage relationship. However, when one of the spouses is diagnosed with dementia, the nature of the caring relationship changes. Mrs. Gladstone did recognize the change, she claims:

"Well, its different now because I have to be much more of a caregiver, keep half an eye on what's going on, where he is, you know, does he need a nap?"

The couples experienced a shift in the caring relationship role as a result of dementia symptoms, from an independent, equal standing role in their relationship to a dependent one. However, the interesting finding about that shift is that although the care role changed, couples lived with and responded to the change as a 'couple' being there for each other during the process. Although changing roles and responsibilities continued within the relationships as dependence and loss were experienced, resiliency was also noticed.

Changing roles and responsibilities

The overarching theme that organized the couples' narratives of integrating dementia into everyday life was changing roles and responsibilities within the marriage relationship. Changing roles and responsibilities meant adjusting to losses in their current relationship, as individuals and as couples. Each couple further described how they carried on as a couple, focusing on what remained for each of them as persons and what remained for them as a couple, for example, minimizing the impact of memory problems on daily life and developing coping strategies to deal with day-to-day difficulties. Responsibility for the management of the home, including paying bills, meal preparation, grocery shopping, cleaning, etc., now became the caregiver's. Spouses assisted with some household chores under supervision. The act of supervision by the carer spouse caused

frustration for the spouse with dementia, a reminder of his or her loss of independence. The caregiving role was seen as fundamentally a different experience for spouses who had cared for their partners with dementia prior to Alzheimer's disease. Mrs. Gladstone described her role change in her relationship with her husband as now being *a caregiver in a mothering role*. Couples tended to negotiate changing social roles and described losing contact with much of their wider social network. Couples became more dependent on each other, more isolated and lonely.

Dependency and loss...The Peters

In the following, the Peters describe changes in their marriage relationship as a result of dementia:

Mr. Peters: She has become more dependent on me. I noticed that. She really doesn't want to stay alone too much. Like if I go out, she doesn't really appreciate it. She doesn't complain too much, but she seems to want to have someone around a lot, that's what is happening, and to go out and visit or something like that, that's not really her.

Mrs. Peters: I've never been that way to go visit.

Mr. Peters: Oh, we have friends that we go for breakfast with quite a bit.

Mrs. Peters: They're good though.

Mr. Peters: Oh yeah. Well her mother's in the same boat as you.

Mrs. Peters: Oh that's why. Yeah they know I have trouble.

Mr. Peters: They understand what it's like, you know.

The Peters friends were understanding and familiar with the signs, symptoms and changes of behavior that can result from dementia. Symptoms can lead many spouses with dementia to behave in socially inappropriate ways. For example, they may walk up to a stranger in a restaurant and make a rude comment such as, "*Gosh you are fat*," or "*We don't like people like you in Canada.*" This causes no end of grief and

embarrassment for the caregiver, who does not care to experience that kind of a public incident.

Mrs. Peters recognized she had troubles. She had lost some of her cooking skills due to memory problems as she described in this narrative:

J: What do you do to help your memory? Do you do certain tricks, certain little things around the house?

Mrs. Peters: Not really, I just keep going. I keep everything in, if he dries or something, sometimes he doesn't put something right in the same place.

(Mr. Peters laughing)

Mr. Peters: Okay. Those are things you know. And then sometimes I have this meat or something and I had it in my mind what it was gonna be, you know, and then it could be a frying pan and then all of a sudden and it dawned on me, I was gonna roast it, wasn't I? Things like that, you know what I mean? And then I pick myself, now I'm on those pills, I hope that stops it where it's at because I think once you've lost it, I don't know if you'd be able to, you know. Now this is the silly thing, I mean, and then I go through almost all my drawers, now where's my knives? This one, that one, oh no, it's over here. Usually, then it dawns on me, that's where I do my cutting, the knives must be in the drawer. Like you know, I think, well, that's where I, you know.

J: How do you see the changes?

Mrs. Peters: He's a little upset with me, I know. I can hear it in his voice.

Mr. Peters goes on to defend himself in his narrative, claiming that when he went into the kitchen to look for something, he would find it had been "*shifted*" to a new location. That caused his upset. Mrs. Peters claimed it had been difficult to reason with her husband because she believed her husband was not putting things away in the kitchen where they belonged. That caused her to be upset. This incident suggests poor insight into some of the deficits experienced by Mrs. Peters. People with dementia often use strategies to try and explain their loss of memory to justify their mistakes. In Mrs. Peters' 'story line', she constructed herself as competent, non-forgetful and experienced in the

kitchen. She understood and could tell that her husband was upset with her at these times. Mr. Peters understood he could not win an argument with his wife in this type of situation. Mr. Peters was unaccustomed to asserting himself in his marriage relationship. It was difficult for him to acknowledge their common reality was not shared and that his wife's behaviour was not under her control, but a function of the dementia. His inability to communicate effectively made him feel frustrated. Nevertheless, he managed to maintain an affectionate emotional concern for his wife throughout his narratives even when his wife's symptoms prevented her from rational verbal communication. He was correct to do this because if he was to try to prove her wrong through rational explanation, she would react badly as she was not able to follow rational thought. As Davidson (1994) suggests, "they know their feelings and you cannot argue them out of their feelings" (p. 109).

From a constructionist point of view, Mrs. Peters' expression of "I" throughout her narrative was an expression of her personal identity. According to Goffman (cited in Sabat & Harré, 1992), one's personal identity, which is experienced as the continuity of one's point of view in the world of objects in space and time, persists 'behind' the publicly presented repertoire of one's personae (p. 445). The function of 'I' in talk is considered to be an indexical expression sometimes referred to as "token reflexes", the meaning of which is completed only in the context for which it was used. "Thus if the Alzheimer's disease. sufferer can be shown to employ first-person indexicals coherently in his or her discourse, on the constructionist account, the A.D. sufferer has displayed an intact self" (Sabat & Harré 1992, p. 447). The analysis of this situation from a constructionist point of view meant that even though Mrs. Peters experienced a disruption in recall memory, information-processing, and word finding, her dementia did not result

in loss of self. Mrs. Peters was engaging in adaptive measures to sustain her self-presentation in everyday life to satisfy the needs of the particular social context she found herself in. Mrs. Peters' use of indexicals concurs with Sabat and Harré's (1992) argument that the Alzheimer's disease self, or personal identity, remains intact far beyond the disintegration of many cognitive and motor functions.

Dependency and loss...The Martins

Mr. Martin talks about how he and his wife collaborate on the changing roles and responsibilities in their marriage in the following narrative. As in the past, they continue to 'do things together.'

Mr. Martin: Sometimes when I come home, I say, 'What did you watch? Today is a special day. It's Monday, and that's a laundry day.' But we had to do a couple of chores in the morning so we did it together and then I sort of say, 'Okay, we're going to bring my car in for a tune-up. We have to go to the bank,' and I'll write it down for that day, and then you do the laundry.' So we cross out the other day before cause that's all she needs to do is focus on that day. And that's what she does. She took the laundry down. She washed it. She ironed it. She wanted to watch Oprah, I guess, and took the wrong switch. She phoned me. I couldn't understand what the problem was, so I couldn't help her. So that's when I said, 'Okay take out the shrimps, I'm coming home early, so you can still see Oprah.' But it's not the most important. So we do work on a routine. As we always like to be together, it is now that she finds it more important to be with me.

Mr. Martin also talked about how his wife had become more dependent on him. As a result he had lost his independence and it was now necessary to 'be on call' during absences from his wife. He worked out a routine for his wife to minimize the calls and help keep her busy and focused doing what she was still capable of doing around the house. Mr. Martin went on to say that he learned about cooking by watching his wife cook and entertain: "*She put things together in such a brilliant way in no time at all she was able to feed 20 people around the table just like that.*" Mrs. Martin responded, "*It's gone*", to which her husband responded, "*Not quite, no, no, but the role has somewhat reversed.*"

For Mr. Martin, getting through the day meant daily problem-solving. Mr. Martin constantly searched for solutions to cope with problems his wife experienced. He was not always able to understand what they were when she would phone him. The task of the caregiver is to try and find that meaning and meet the need expressed by it. Mrs. Martin was trying to make sense of an increasingly bewildering world; the resulting behaviours of not being able to communicate what she needed caused her to become frustrateded, lonely, and frightened to be left alone. She displayed symptoms of depression reflecting her real sorrow and grief at losses with the expression, "*It's gone*", meaning like so many other things lost in her life, she now was no longer able to cook and entertain. Mr. Martin wanted to fix the grief he felt his wife was experiencing and remarked, "*Not quite.*" He suggested that the role had reversed somewhat, and with his help she could still cook and entertain.

From an interactionist perspective Mr. Martin was attempting to make sure both he and his wife "keep their place" in a reconstructed relationship. This new relationship was now considered within the context of a pre-existing relationship, prior to dementia. In that relationship, both spouses had an understanding of who the other was and the expectations of how that person would behave. The Martins relational selves had now been threatened, and this called forth the need to negotiate some sense of order out of the chaos they found themselves in. Working on daily routines and to-do lists together seemed the natural thing to do.

Dependency and loss...The Burns

The Burns' narrative on changing roles and responsibilities as a result of dementia focuses on Mr. Burns' dependency on his wife for direction and his loss of short-term memory. Mrs. Burns described herself as a traditional stay-at-home mom. Before her

husband retired, he did no housework, "*absolutely none*", she explained. Now "*he helps a lot,*" he vacuums, she dusts, and makes meals, and he generally clears up after. Mrs. Burns acknowledges frustration with her husband who repeatedly asked the same questions over and over, for example, "*What are you doing*?" No answers would resolve the continued repetition of questions "*every three minutes.*" In Alzheimer's disease, the short-term memory goes first, followed by the long-term memory. Some people retain some parts of long-term memory to a surprising degree. Mr. Burns was one of those individuals. His wife told me he had amazing recall of golf games, that he still could remember his plays in a game with great detail. The pattern of forgetfulness varies according to an individual's mind patterns, and can change from day to day according to how the person is feeling. When memory goes, we can also forget what year it is. It is not uncommon for individuals to believe they are living in the early years of marriage where they feel they have responsibilities for home and work and taking care of children. It is best to acknowledge and support the belief without correcting the error.

Repetitive questioning, one of the symptoms of early AD, is usually extremely irritating as Mrs. Burns suggested. Although she answered her husband's question immediately the answer was quickly forgotten and the same question asked again. A common response to constant questioning is to distract a person hoping, they may forget the question and quit asking. It often works.

Dependency and loss...The Gladstones

The Gladstones narrative on changing roles and responsibilities resulting from dementia raised three important dependency and loss issues; (1) loss of driving privileges; (2) loss of appetite; and (3) outbursts of anger. In the following narrative, the Gladstones comment on loss of driving privileges:

J: Any other difficult times? Any crisis?

Mrs. Gladstone: Peter did, and I've heard from every woman I know that, the killer is the driver's license. Peter doesn't have a driver's license anymore. But that was hard on him, yeah, that was hard on him.

J: Do you agree that was a pretty tough time, when you lost the driver's license?

Mr. Gladstone: Yeah. Well, I don't go out very much, you know.

Mrs. Gladstone: You loved going to stores. He was the world's biggest shopper. He knows Safeway backwards. He loves to shop.

Mr. Gladstone: That's the damn nuisance you know. You've got to wait for Ada and ask her to get something. You don't like doing that. I just use to go and shop, just locally. About you know, half a mile away, very little driving as such.

It is hard to lose access to driving a car for Mr. Gladstone. Having Alzheimer's disease does affect judgment in too many ways to maintain safe driving. Mr. Gladstone's memory was affected, as well as his judgment. This may have caused him to drive erratically while trying to work out where was going. It could also affect his awareness of what proper driving actually was. Alzheimer's disease specialists disagree on automatically removing driver's licenses with the diagnosis. Many physicians evaluate their patients based on the score from the SMMSE (Standardized Mini Mental State Exam) an assessment tool used in diagnosis of Alzheimer's disease. If the patients score is >24/30 and he or she has no problems with function or behaviour, he or she may be deemed ok to drive with follow-up. A physician has a moral obligation to report unfit drivers to licensing authorities.

Mrs. Gladstone commented that a friend's husband with dementia, was "*also getting a little mental,*" was surprisingly allowed to drive a car "*and his GP, now he's not*

under a geriatrician, has said, yes he can drive, but he must have someone in the car with him. Well, that's a new one on me. I'll be damned if I'd ever get in the car with him."

Mrs. Gladstone also commented on the fact that she had to remind her husband to eat. Problems with eating can take many forms – eating too little, too much, too slowly, too often and eating too much sugar. A number of individuals with Alzheimer's disease lose interest in food, but will eat if it is put in front of them. This was the situation with Mr. Gladstone. Individuals with Alzheimer's disease living alone often starve themselves, even though their fridge is full of food.

The most stressful change experienced by Mrs. Gladstone was her husband's angry outbursts. One angry outburst incident was over the purchase of a new TV, and the outburst lasted an hour. Mrs. Gladstone reported the incident to her doctor and her husband was then prescribed a sedative. Mrs. Gladstone mistakenly believed her husband was intentionally getting angry to win the argument. One explanation that could help explain Mr. Gladstone's behaviour is that of his progressively lowered stress threshold (PLST). According to this model, the diminished capacity Mr. Gladstone experienced, to remember, make judgments and choices, solve problems, adjust to new situations, and understand complex ones increased the stress he experienced in trying to deal with situations that appeared challenging (Mittleman, Epstein, & Pierzchala, 2003).

Fabiano (1996, p. 52) describes the aggressive cycle of individuals with Alzheimer's disease, as shown in Figure 10. He claims that anything that confuses the mentally impaired further (called a circumstantial episode), increases their feeling of being out of control, pushes their anxiety level to a panic state, causing them to become aggressive, wander, or withdraw. Fabiano refers to the progression of events as a crisis response.

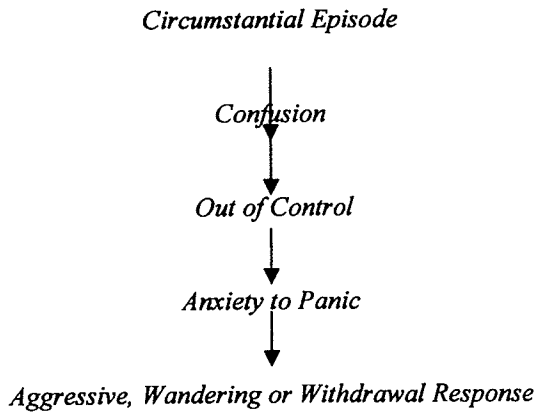

Figure 10: The aggressive cycle

Dependency and loss... The Campbells

Mrs. Campbell had started to wander away from her home as a result of becoming confused. Mr. Campbell gave his wife tasks, to do such as mailing letters, when she appeared to be headed for the door. This distracted her and she was able to focus on the task, mail the letters, and return straight home. Her husband was able to see her at the mailbox and could monitor her wandering. The Campbells had always enjoyed gardening at their home in the city and their cottage at the lake. Gardening was one activity where the couple could still enjoy, as he recalled:

Mr. Campbell: We've got all these plants that have to go out in the garden and I'm starting to rake the lawn up, so we've got a big piece of property and (Ada) *can work out on her own better in our garden than anywhere else. She can go out there for 2 or 3 hours and I don't have to worry about her. She doesn't go wandering and gets a lot of useful things done.*

Safety is the biggest worry for some caregivers. Mr. Campbell had alerted his neighbours as to Mrs. Campbell's situation, and reported getting much help and loving support. His neighbourhood became a friendly guardian. It is important for every person with Alzheimer's to wear an identification bracelet as Mrs. Campbell did. It is also

important to have a clear recent photograph on hand in the event that the police become involved.

Mr. Campbell referred his wife's dementia as "*a slow drift.*" Graham and Bassett (2005) might describe the "drifting away" experienced by Mr. Campbell as detachment. Detachment is described when one or more people in the relationship no longer engage with others or their environment. Although persons with dementia may appear as being no longer engaged, they may view themselves as being very much involved. Mrs. Campbell viewed herself as very much engaged as she described in her narrative: (This answer was in response to the doctor's question, "*How do you remember things you're supposed to do*?")

Mrs. Campbell: And I said, well, I'm left handed, so I pick up the phone with my right hand and I have a paper right there and with my left hand, if someone wants me to usher, us usher for church, or bring cookies to University Women's Club or whatever, I write it down.

Mr. Campbell reported being extremely unhappy in his marriage. His wife reported being very happy. Based on the joint narratives, I would have expected the couple to answer with similar responses. Perhaps the contradiction was the result of his wife's detachment. His wife had drifted out of their marriage relationship.

Dependency and loss...The Smiths

The Smiths experienced two important changes in roles and responsibilities resulting from dementia, marital conflict and depression. The Smiths experienced conflict over "*little things that come up*" as Mr. Smith explained:

Mr. Smith: Well her housekeeping is down, because she was an immaculate housekeeper, and again you were asking about little things that come up. Like yesterday, I phone for her to the hairdresser and we're going on Friday. She's gonna have a perm. Today she said I don't want a perm. I just want my hair set. I said, 'Well, get the perm and you'll be good for three months.' So that's the kind of argument, if you call it an argument.

Mr. Smith: He told me that I wanted a permanent. And I said I don't want that.

Mr. Smith noticed his wife had "detached" from their former relationship. She was no longer initiating communication, was reacting to conversation rather than initiating, being led or cued as she had been throughout the interview. She was defending her *self* to "save face" as a response to her advancing cognitive impairments. According to Goffman (1967), "when a person senses he is in face, he typically responds with feelings of confidence and assurance... When a person is in wrong face or out of face, expressive events are being contributed to the encounter which cannot be readily woven into the expressive fabric of the occasion. Should he sense he is in wrong face or out of face, he is likely to feel ashamed and inferior because of what happened to the activity on his account and because of what may happen to his reputation as a participant" (p. 8).

The other relevant issue related to dementia is depression. Depression is a common condition among people at all stages of dementia (Alzheimer's Society, retrieved June 10, 2007). Depression is a more persistent condition than feeling low or down from time to time. In depression, a number of feelings, such as sadness, hopelessness, or lack of energy, dominate a person's life and make it difficult for him or her to cope. Mrs. Smith displayed a mild form of depression with the following symptoms; loss of interest or pleasure in activities that were once enjoyed; a sad hopeless or irritable mood for much of the time; problems with remembering, concentrating or making simple decisions; weight loss; and always feeling tired (Alzheimer's Society). Mrs. Smith reported, "*I have no problems sleeping. I'm so tired all the time. I don't know why*. Her husband responded, "*Lots of nights, she's in bed by 6:30.*"

Changing relationships... *"drifting away"*

"Friends, it's an awkward thing. Since we can do less things, they tend to be drifting out of out life." (Mr. Campbell)

The nature of each of the six couple's marital and social relationship changed after a diagnosis of Alzheimer's disease. Certain aspects of the marital relationship changed such as reduced shared activities, loss of emotional support, loss of verbal communication between the couple, and change in marital satisfaction. Relationships with friends had also changed as a result of dementia. Mr. Campbell described the change as friends *"drifting away."* Mr. Peters described that *"people distance themselves."* The Peters' narrative in the following excerpt provides insight into the social stigmatization of dementia and a possible explanation as to why people distance themselves:

Mr. Peters: And to a certain extent people will distance themselves from you because of the situation. They don't feel comfortable with it, right?

Mrs. Peters: They don't know how to deal.

J: Do you feel that?

Mr. Peters: I feel that people do that.

Mrs. Peters: What do you think I feel like?

Mr. Peters: No, no, but I feel that, like people distance themselves because of that reason.

Mr. Peters: Because I'm not as, maybe come up with thoughts fast enough.

Mr. Peters: Oh, no, no.

Mrs. Peters: When we're talking or something.

Mr. Peters: No, as far as your communication, I mean you still communicate.

Mrs. Peters: Well, I thought maybe because I repeat myself.

Mr. Peters: Well, maybe you come on a little strong sometimes that way. You harp a little bit, and then they can't deal with that.

It was evident Mrs. Peters was hurt by the discussion of her loss of social skills. Early on, people with dementia can put on an impressive social façade that can be quite deceptive as Mrs. Peters had tried to do. Caregivers can become annoyed as they feel problems are not believed by friends and family and even professionals. Eventually, symptoms progress and social skills become impaired. From an interactionist perspective, maintaining social skills means taking the role of the other. Taking the role of the other, is imagining the world from the perspective of another. As we imagine the world of the other, so we act: as we place ourselves in the others role in order to see the world from his or her perspective, so we know when to flee, how to become friends, how to become part of a group, how to act morally, how to win, how to understand, how to share, and how to communicate (Charon, 2004). Mr. Peters was able to take the role of his wife as he understood the world from her perspective as well as her fluctuating periods of awareness. Although Mrs. Peters maintained many of her social skills, she had lost others and consequently she felt devalued - stigmatized.

Stigma has traditionally been defined by Goffman as a sign or a mark that designates the bearer as defective and therefore meriting less valued treatment than "normal people". The psychological and social consequences of stigma involve the responses of both perceivers and stigmatized people themselves. Mrs. Peters aspired towards normalization in her narrative and experienced anxiety in interaction when her self-esteem and happiness were threatened. She felt stigmatized by her friends but understood by her family. Fear of rejection can create a chain reaction, when the initial sense of rejection may cause stigmatization to act awkwardly, as Mrs. Peters did, and ultimately this reinforced and perpetuated her awkward behavior. Non-stigmatized individuals perpetuated that rejected behavior further stigmatizing Mrs. Peters.

Some individuals with dementia are not aware of changes in their social functioning. Mrs. Martin recognized friends may not come over often but she believed they were still around. To some degree, she stated, "*You just go on.*" Mr. Burns had no concerns with his modest social life, believing he was slowing down due to aging.

One of the important factors for all couples that helped compensate for loss of social interaction with friends and social networks was the increased supportive roletheir families assumed. All couples had children and grandchildren living in the city who keep in close contact with them. Family assisted with such day-to-day tasks as making meals, transportation to appointments, shopping, problem-solving, and visiting. Family played an important role in how couples viewed their future plans as well.

Future plans... "living day-to-day"

"*Well we're gonna hang in here as long as we can. It's as simple as that.*" (Mr. Campbell)

Four couples, the Campbells, the Burns, the Gladstones, and the Martins agreed they would hang in as long as possible in their current home. They all had children living not too far away. Two couples, the Peters and the Smiths, were planning moves at the time of the interviews. The two couples were moving to be closer to their children.

Mr. Martin hoped to retain some independence for as long as possible. He wanted to give his wife the feeling she could cope on her own so that when he was gone she could manage. At the time of one of the interviews, they had been separated for five hours during the day. They had called each other several times during that period of time, and if there would have been a need for something he would have called one of his daughters, son-in-laws or grandchildren, or he would go home. He was happy not to be

tied down and be able to make the decision to leave his place of business. If he was in a meeting at the time his wife called he could leave: "*They understand, I can say, 'Sorry fellows, I have more important things to do', and I excuse myself and leave. They understand what is important for a man and a husband and that's all there is to it.*" When it gets to the point when his wife requires longer and more care, he will arrange part-time help to come to the home. If no suitable person could be found, he assumed the family would take turns; his turn would be "*the major one.*" The family was in agreement, he claimed; they wanted to make life as pleasant as they possibly could.

Mr. Campbell and his family also plan to make life as pleasant as possible for Mrs. Campbell. They intend to continue to maintain the home and lifestyle as in the past, such as Sunday night dinners, going to the lake in the summer, and gardening. At the time of the interview, Mr. Campbell's daughter and daughter-in-law were planning a big party for Ada to celebrate her 80th birthday.

The Gladstones have "*extremely good neighbours*" and their daughter lives down the same street and did not plan to move. The Burns had not thought about the future but if they needed help in the future they imagined their children and grandchildren would all "*pitch in and take turns helping out. We've never had to ask for help in any way, so it's not something we've even thought about.*"

In the following excerpt, the Peters reflect on plans for moving:

Mr. Peters: Well, there could come a time like as we age and as we deteriorate, the results can be that either one of us could land up in a seniors' home. I mean, if her dementia increases, I mean there comes a point and time when you can't look after a person, right? And that's where the nursing home comes in, and up to that point, I guess we'll have to trudge along, just make it easier for ourselves instead of complicating the home situation, make it a little easier. Like moving into a single level or a bungalow style home where it's just a little bit easier.

The Peters and Smiths were looking to move to a community close to where their children and family lived. Mrs. Peters believed she might find more support and understanding:

Mrs. Peters: You can make friends more easily, and like with me to; I would find maybe somebody that has the same problems, outside the family, cause the family's always telling you, 'oh you should be doing this and you should be doing'....I don't buy that. Just what makes things worse to me, what they should be doing.

Integrating dementia into everyday life left most of the couples little time to plan for the future. They could not imagine the kinds of support they would require or where it might come from, with the exception of support from their children.

Summary

This chapter has described each couple's integration of dementia into everyday life. Couples' narratives described how they reappraised and reconstructed meaning through changes in their marital relationships. These changes included themes of changing caring relationships, changing roles and responsibilities, changing social relationships, and changing future plans. It began with a review of the DAS and ROR scores which shifted attention away from the narratives of change to uncovering scores related to satisfaction and commitment in marriage. Findings from the DAS scores indicated dementia had less of a negative impact on marriage satisfaction and more of an impact on the degree of happiness a spouse experienced in marriage, all things considered. The pattern of the ROR scores found most couple score midrange, suggesting an orientation between traditional and egalitarian. Couples' commitment overtime to the institution of marriage remained the same, reinforcing the global theme *marriage is for life.*

The couples experienced a shift in the caring relationship as a result of dementia from an independent equal standing role in the relationship to a dependent one. Although the care role changed, couples responded to the change as a couple being there for each other as they had in the past. Changing roles and responsibilities resulted from adjustment to losses as individuals and as couples. Changes included role change to caregiver, changes to the relational and personal selves, repetitive questioning, loss of driving privileges, wandering, depression, angry outbursts, and detachment from the marital relationship. The couples also experienced changing social relationships as friends drifted away. Family relationships changed as couples looked towards their families for future care and support.

Chapter Eight

Findings and Discussion: Factors contributing to commitment of the marriage relationship and sustained dementia care

"*You cannot be Totally committed SOMETIMES*" (A Course In Miracles, p. 160)

Introduction

Although couples experienced a shift in roles and responsibilities in the marriage relationship resulting from loss and dependency issues, their commitment to their spouses remained enduring. Certain patterns of caring were reflected throughout their marriage biographies that helped sustain them in their ability to be there for each other now that one of them had Alzheimer's disease.

In this chapter I process the narrative material of the couples' stories analytically into content categories relevant to the contributing factors to commitment in marriage that helped sustain dementia care. The categories expand on the themes and plots from the thematic analysis in Chapters 5-7. In particular, I present and elaborate on the findings on the four factors which contribute to commitment to the marriage relationship which I derived from the couples' stories. These factors are, namely, marriage means: (1) partnership for life, (2) reciprocity, (3) resilience, and (4) forgiveness. Next, I build upon empirical findings of research on marriage and dementia care and compare my own findings to this research. Lastly, I reformulate my conceptual model on the co-construction of commitment to the marriage relationship on the dementia experience and its relationship to symbolic interaction.

Commitment qualities that contribute to sustaining dementia care

1. Marriage means a partnership for life

"*It's kind of a partner deal.*" (Mr. Smith)

For the couples partnership in marriage meant a belief in the sanctity of marriage as a sacred institution, as well as personal sense of obligation to honour their marriage vows, which fits with one of the broad dimensions from a review of the marriage literature on the conceptualization of marital commitment (Adams & Jones, 1997). The couples' belief in marriage as a partnership for life was a major content theme rooted during the 1950s and 1960s, when the traditional nuclear family was idealized. The couples were positively influenced by the importance of marriage from their family of origin. Although the early years were witness to tough times and hard work, the couples developed partnerships of doing things together and had resources to establish and maintain a family and lifestyle of their choice. Commitment to a partnership for life meant changing with changing circumstances throughout the marriage relationship. The Peters provide an example with their philosophical insights into changing with circumstances:

Mr. Peters: Circumstances can change people's personalities, certainly. Let's say you have a lot of difficult times, you were abused or something, then you're gonna react differently. I can see it that way, but in generally, you're not gonna change a person that drastically from what they really are.

J: And you didn't try.

Mr. Peters: Well (laughing)

Mrs. Peters: Unless they hid it quite a bit beforehand, like you didn't know them as much as you thought you knew them, and then all of a sudden, when she or he was, you know, grabbed this fellow or he grabbed this women, hey, hey, she's not like she used. We do age. We change too when different circumstances come in the family.

J: What do you mean you change when you age?

Mrs Peters: Well, the person's personality changes as well. Like when he was working, that was easy because he was at work and all that kind of blah, blah, blah but when you retire it's a little different again. See like now, he's on the go. I can't do it, so I have to, you know, sort of, a little bit.

Mr. Peters: Pull back. But as far as your personality, I don't think it changes that drastically unless there's real adverse conditions that enter into a marriage that affects the personality where you build up a defense or something.

Mrs Peters: A wall sort of thing.

The Peters' interaction suggested they believe couples change with changing circumstances in marriage, but their basic personalities remained intact unless an adverse condition enters that affects the personality of one of the spouses (such as Alzheimer's disease). For example, when normal day-to-day interaction became tense during meal preparation, Mr. Peters *pulled back*, instead of getting angry at his wife. The key message found in this account of the experience of change was based on humanitarian values in marriage that led the Peters to understand and accept reality as it was. Life was not always easy.

In line with a dynamic view of continuity theory of normal aging (Atchley, 1989), the couples managed adaptive strategies to change with changing circumstances throughout the marriage relationship. Substantial change occurred in life without causing serious disruption in the stable directional context within which in their lives various episodes were played, even in the context of dementia. In other words, and according to Atchley (1989), there was an ebb and flow to the drama of the couples' everyday lifes, and also substantial continuity of both character and plot (p. 184). In part this continuity reflected in the couples' lives was a result of their positive expectations of marriage. Theoretical work within the literature on close relationships, interdependence theory,

suggests that partners determine their satisfaction with the relationship by comparing the outcomes they receive in their relationship with the standards they have for that relationship (McNulty & Karney, 2004, p. 730). Each couple was satisfied with their marriage relationship, all things considered, even after a diagnosis of Alzheimer's disease. This finding is consistent with findings from a study investigating perception of the influence of dementia on marriage (Eloiemi-Dulkave et al., 2002). In this study, dementia did not significantly affect the general atmosphere of the marriage. The positive changes and preserved aspects of marriage helped caregivers to continue to provide home care.

The Gladstones' narrative provided an example when partnership in marriage was absent. Mrs. Gladstone singled out her husband's lack of interest and knowledge of his family of origin as a major irritant in her married life. I asked, "*Would you do it again*?" (meaning marry each other). Mr. Gladstone said he would, but Mrs. Gladstone responded:

Mrs. Gladstone: Oh boy. I think I'd ask an awful lot more questions. I didn't realize there was an awful lot (Peter) wasn't telling me. I mean it's just that he didn't, I don't know. I mean, I think that when we'd been married about three weeks I guess, cause we were back from our honeymoon, I mean, I said something, 'Your father's got a brother?' And he just went on walking, oh yes, I think he did. I said, 'Well what do you mean you think?' He said, 'Oh I think there were three brothers and maybe a sister.' And I'm running on like this as he's walking. I'm saying, 'Alright, stop, stop. You mean your father, you've got aunts and uncles?' 'Yeah, I guess so'. I said, 'You've probably got nieces and nephews.' I mean probably. 'I don't know. I never asked.' Finally after a few years, I said, 'When you die, I'm gonna have it written on your tombstone, I never asked. To this day.'

It turns out Mrs. Gladstone had her own idea of why he never asked about his family of origin "*Because he was terrified of his mother, she would give him hell.*" Mr. Gladstone agreed. He told of his early years, when at 18 he left home after living with his mother,

and joined the Air Force. After he was shot down and taken prisoner of war, he went back to England - on VE Day and went to university after that.

Almost all family scholars agree that family of origin is very important in launching children into adult life with the attitudes, behaviours, and skills that facilitate success in adult romantic relationships (Busby, Gardner, & Taniguchi, 2005). Exposure to ineffective patterns and processes within the family of origin does not stop individuals from forming adult partnerships. They do, however, infiltrate the manner in which the adult relationships are structured and experienced (Sabatelli & Bartle-Haring, 2003). Mr. Gladstone believed he did not have the knowledge and skills to be a good husband, and that his wife deserved better than him. Mrs. Gladstone found her husband to be reliable, but controlling and insensitive to her needs. The Gladstones enjoyed many things together, but reported doing things separately on the DAS questionnaire.

The couples found their partnership for life changed with the gradual and cumulative signs and symptoms of dementia entering into their relationship, disrupting normal routines and practices. Activities were maintained for many of the couples through continuation of daily tasks, engaging in pastimes like gardening, walking, reading, and seeing friends. According to Keady (cited in Hellstrom, Nolan, & Lundh, 2005), in most caring relationships the main motive for the caregiver is to maintain involvement for the person with dementia by creating ways in which the sense of agency and self could be sustained for as long as possible. Mr. Campbell organized daily trips to the mail box for his wife, Mr. Smith and Mr. Martin organized and monitored their wives help around the home, such as vacuuming, laundry, doing dishes, and helping with meals.

Relationships were one area where change could not be ignored, and all of the couples were engaged in some way in negotiating changes in their relationships.

Increased dependency and negotiating changing roles and responsibilities with the awareness of dementia were generally appreciated and accepted by the spouse with dementia. However, Mr. Gladstone and Mrs. Martin felt they were a burden to their partners. On the whole this analysis is consistent with findings that report people with early-stage dementia change and adapt their coping strategies over time (Clare, Roth, & Pratt, 2005). The main categories to change were changes or threats to change in normal routines or practices (Norman, Redfern, Briggs, & Askam, 2004).

2. Marriage means reciprocity

Reciprocity, or the 'give and take' in each couples' marital relationship, was present despite one spouse's dementia. Shared meaning was still experienced by both spouses, although relations of *equal reciprocity* were difficult to attain as the spouse with dementia was no longer able to reciprocate equally. That didn't appear to be a problem. In fact, Graham and Bassett (2006) claim reciprocity is seldom equivalent between people engaged in an ongoing relationship. In my examination of the dynamic co-constructed narratives and results of the quantitative measures , relationships were found to be maintained and interactions built on everyday events. The everyday events examined were organized around four major dimensions of the marital relationship: (a) household tasks, (b) companionship, (c) affection and sexuality, and (d) commitment. These marital relationship dimensions were based on Spanier and Thompson's (1976) Dyadic Adjustment Marital Adjustment Rating Scale, which the couples filled out. Agreement of consensus was assessed with one of the subscales that included handling family finances, household tasks, and other consensus issues such as making major

decisions. Six response options were provided, ranging from always agree (6) to always disagree (1). The maximum consensus score on this scale is 75.

(a) *Household tasks*

Interestingly, the four couples, where spouses completed the questionnaire separately, indicated high agreement on major consensual issues related to the marriage relationship. The dyadic consensus refers to the degree to which couples agree on matters of importance in their marital relationship. Although the scores were close, for example Mr. Burns scored 62/75 and his wife 57/75, she did not answer one of the questions. The three couples had at least one answer missing as well. The household tasks most frequently agreed on by the Burns, and Campbells were household tasks, leisure-time, and same interest activities. Mrs. Peters reported frequently disagreeing on household tasks which was not a surprise as the couple reported having difficulties working together making meals and keeping things in their proper places in the kitchen. There was a high level of consensus in areas such as religious matters, making major decisions, amount of time spent together, friends, aims, goals and things believed important, and philosophy of life. The Gladstones did not always agree on everything, and Mrs. Gladstone reported almost always disagreeing with ways of dealing with parents or in-laws. This issue is overrepresented in her narratives, as she constantly talked about the mystery behind her husband's family and his refusal to talk about them. His response, "*I don't remember*", angered and frustrated her. Most couples worked together sharing household tasks and responsibilities. Although the caregiver now assumed the major responsibility for household tasks, all spouses with dementia were physically well and with supervision and direction, were able to support their spouses and made them feel useful. Both the Martins and Smiths completed their questionnaires together. Both couples always agreed or

almost always agreed on the household tasks. They discussed some questions and arrived at a consensus before selecting their answers.

(b) Companionship

Marriage by its nature provides companionship for two people. But whether the marriage merely provides for the presence of another person, or whether a couple living together share common beliefs, values, and feelings, makes a profound difference in the quality of the relationship. Companionship for the couples meant doing things together, always being there for each other through thick or thin and being partners for life. The cohesion scale, specifically the DAS subscale, which measures the degree to which a couple engages in activities together included: frequency of discussing something, exchanging ideas, laughing together, doing something together outside the home, and working on a project together. Response options ranged from more often than once a day (5) to never (1).

Five couples' positive responses to the question: "*Do you and your mate engage in outside interests together*?" suggests global coherence for the theme 'doing things together' reflected in the analysis of the couples narratives. The answer 'most of them', was reported as the most common response by the Martins, Burns, Campbells, Peters, and Smiths. The Gladstones both agreed that they engaged in 'very few' outside interests together. These reports were consistent with the findings from the analyses of the couple's transcripts and the pattern of interaction established throughout the couple's married life. I described the Gladstones earlier as the couple who lived together but enjoyed separate lives. The other five couples engaged in outside interests together throughout their married lives.

Interestingly, husband and wife dyads gave congruent reports about how much companionship they had. Laughing together was rated as 'once a day' or 'more often' occurring more frequently than any of the other items. These results support Wright's (1993) findings that laughing together indicates a way of coping for caregivers and individuals with Alzheimer's disease. The author also reports loss of companionship for caregiving spouses. Although the couples were still engaging in outside activities, they were of a different nature and quality compared to earlier years. As couples aged, they tended to live quieter lifestyles. Going for a ride in the car was considered an opportunity for companionship for the Peters. Shopping together was now a norm in most households. Participating in social events meant getting together for family celebrations and visits with the grandchildren. Loss of mutually satisfying companionship became apparent in the caregiver's narrative accounts of dependency with checks on the indicator in the DAS of frequently not having a stimulating exchange of ideas. Inconsistent with Wrights (1993) findings, the caregiving spouses in this study were mostly accepting or content to be at home with their spouses. In Wright's study the caregivers had a strong need to escape the relationship.

(c) Affectional expression

Affection expression in the DAS is defined as the extent of agreement regarding demonstration of affection and sexual relations. The subscale includes: demonstration of affection, sex relations, being too tired for sex, and not showing love. Mrs. Gladstone reported that as a couple they occasionally disagreed on demonstration of affection and frequently disagreed on sex relations and not showing love. Mr. Gladstone commented that he was too old for sex. The Campbells, and Martins, Smiths, and Peters always or almost always agreed on demonstration of affection, sex relations, and showing love.

This is consistent with findings from Eloniemi-Sulkava, Notkola et al., (2002) that dementia seems to have surprisingly little impact on whether a couple continues to have intercourse when compared with the general aging population. The four couples demonstrated personal commitment to their spouses throughout their narratives and scored higher on marital satisfaction suggesting, love did not diminish over time.

Sharlin, Kaslow and Hammerschmidt (2000 p. 58-59) reported on a multinational study of long-term marriages and suggest the following eight characteristics appeared most consistently:

1. Lifetime commitment to marriage
2. Loyalty to spouse and the expectation of reciprocity
3. Strong, shared moral values
4. Respect for spouse as best friend, and self-disclosure to each other
5. Commitment to sexual fidelity
6. Desire to be a good parent
7. Faith in God and spiritual commitment
8. Good companion to spouse – spend a great deal of enjoyable time together over the course of a lifetime

The findings, through narrative analysis of the couples' stories, also pointed to a high level of concordance in each couple's assessment of the above eight qualities and variables that made their marriage work for them. Lifetime commitment to marriage suggests that commitment is the essence of long-term relationships and can sustain a relationship during tough times and a diagnosis of Alzheimer's disease. With the passing of time, husbands and wives increasingly valued each other as unique persons and were highly committed to the future of their relationship. The spouses with Alzheimer's disease were well aware that their partners were the most important persons in their lives, although at times both marital partners became very frustrated with the situation. However, the desire to maintain the relationship and make the necessary effort to be

mindful and responsive to the spouse with dementia led to each couple's wish to 'hang in for as long as they could' at home - together.

The significance of reciprocity

Couples in this study did not undergo a decline in their reciprocal caring relationship as a result of a dementia. There was as suggested by Perry (1999), a cognitive dimension to caregiving in addition to the commonly described emotional and task- oriented dimensions. Care providers interpreted their intimate knowledge of their spouses and subtle changes resulting from dementia, into the plans and approaches to enact their day-to-day lives. This helped maintain the couples' relationships. Spouses strived to maintain continuity to the lives and make meaning of their situations by trying to continue to let their spouse with dementia do as much as his or her could, encouraging the maintenance of personhood (Menne, Kinney, & Morhardt, (2002). This direction of preserving personhood recognizes the interdependence of the caregiving-care receiving relationship by positioning the caregiver as a spouse and not simply a caregiver (Perry, 2002). This fits with the notion of 'constructed reciprocity' (Neufeld & Harrison, 1998), where spouses were committed to an ongoing relationship with their spouses viewing his or her partner as a unique person despite the cognitive impairment. Couples maintained the ability to talk of loving relationships in the present. Positive prior relationships enabled couples to find meaning (Graham & Bassett, 2005) in their caregiving relationships. Normative expectations of reciprocity, of an "old self", where phone messages were remembered and passed on, and items were replaced rather than misplaced, no longer existed. Instead couples recognized subtle reciprocities, such as a shared sense of togetherness. Carers accompanied those they cared for to medical

appointments, restaurants, and took them for drives. Carers often invited friends to the home where idiosyncrasies resulting from dementia were better accepted.

3. Marriage means resilience

According to Patterson (2002), the concept of resilience emerged from studies of children who functioned competently following risk exposure. Patterson (2002) suggests Antonovsky, a medical sociologist, introduced the concept of "salutogenesis" to describe high functioning of many of the survivors of the Holocaust. The phenomenon of doing well in the face of adversity is now called *resilience*. The central assumptions in resilience research have been used to refer to:

- a positive outcome despite the experience of adversity;
- continued positive or effective functioning in adverse circumstances; or
- recovery after significant trauma (Masten et al. 1999, cited in Schoon, 2006, p. 7).

In the view of Canary, Stafford and Semic (2002) resilience in marriage is tied to the manner in which people strategically maintain their relationships, that is to say the manner in which spouses are able to maintain their relationships in the face of day-to-day tasks and normative stressors. "Marital resilience implies a process in which people purposefully engage in *maintenance strategies*" (p. 395).

According to Canary, Stafford and Semic (2002), there are three fundamental relationship characteristics (liking, commitment, and control mutuality), and five relational maintenance strategies (positivity, openness, assurances, social networks, and sharing tasks). The authors propose the following three fundamental relational definitions:

Liking refers to the degree to which a person admires his or her partner.

Commitment corresponds to the notion of personal commitment where the person is motivated by personal factors rather than moral or structural forces.

Control mutuality refers to the extent that both parties agree on who has the right to influence the other, that each person concur about the way decisions are made whether the relationship be defined as traditional or egalitarian (p. 397).

The following are the five relational maintenance strategies proposed by the authors:

Positivity includes acting polite and cheerful, being nice, courteous, and upbeat during conversations, and avoiding criticism.

Openness involves discussing the relationship and sharing thoughts and feelings

Assurances involves expressions of love, commitment, and in other ways implying the relationship has a future.

Social networks concerns spending time with and including mutual friends and family in activities.

Sharing tasks refers to engaging in household chores as well as any tasks that may constitute the responsibilities of the couple (p. 396).

The authors conclude that resilient relationships can adjust to change while retaining their fundamental characteristics. In their view, maintenance strategies function to sustain relational characteristics, thereby continuing to define the nature of the relationship (p. 403).

The couples in the study purposely engaged in maintenance strategies throughout their married lives resulting in marital resilience. Despite tough times and hard work early on, they continued to function effectively, changing with changing circumstances, even recovering after one spouse received a diagnosis of Alzheimer's disease. The majority of couples were motivated to their commitment to marriage by personal rather

than moral or structural factors. The couples concurred about the way decisions were made, whether the relationship was defined as traditional or egalitarian. During the interviews, all but one couple demonstrated a polite, courteous, kind attitude to each other in their conversations and avoided criticism. The couples continued to share household chores, doing them together, now that one spouse of each couple required supervision. These findings support previous literature on long-term marriages where couples scored high on the DAS, indicating that they were satisfied with their marriages (Banchard & Caron, 2001). Factors for successful marriages reported in the literature include the same factors expressed by the couples in the study and include lifetime commitment to marriage, loyalty to the spouse, strong moral values, respect for the spouse as best friend, and commitment to sexual fidelity (p.108). What this study adds to the growing body of dementia literature was that most of the couples reported a continued caring relationship with '*undisturbed commitment*' and resilience to the changes experienced as a result of early-stage dementia, thus maintaining continuity to the marriage relationship.

Living with early-stage dementia was a "*different challenge*" Mr. Martin explained, different from other kinds of illness, such as cancer, which his wife had also experienced. When asked the question in the DAS about how they felt about the future of their marriage relationship, five of the couples circled that they wanted very much for the relationship to succeed and would do all that they could to see that it did. Mrs. Gladstone reported that it would be nice if her relationship succeeded, but she couldn't do much more than what she was doing now to help it succeed.

Interdependence became a central theme in the couples' lives with the onset of dementia symptoms. The beliefs and meaning of dementia couples brought to the situation were often rooted in anecdotal stories told by family members of grandparents

experiencing exasperating dementia behaviour thought to result from hardening of the arteries, a common result of aging. Couples were made profoundly aware of the process of dementia when it surfaced with a parent, aunt, or uncle as Mr. Campbell explains:

J: I wondered how dementia, memory problems, fit into your rhythm of life (an expression Mr. Campbell often used during the interviews)

Mr. Campbell: Well, my mother had the same problem, so we had seen the pattern. I've learned a great deal about it from her... We had two, we had my mother to care for and we had my aunt who's a sister of my father. So my brother and I agreed cause he lived near Montreal, he would take care of the old aunt, who was the first to get in trouble. So he took care of the old aunt and I took care of my mother. It was a division of labour.

The Campbells' children and grandchildren are now helping with the division of labor in supporting their mother and grandmother, as Mrs. Campbell explains:

Mrs. Campbell: We've taken our grandchildren with us on trips because I get lost in the bathrooms, and can't find the exits.

Mr. Campbell: We spent a lot of time last night working on that, getting ready to go to Europe on Monday. Our daughter in town was over here last night arranging our trip to Europe.

Losing way-finding ability and getting lost, such as Mrs. Campbell experienced, is common for people with dementia. Losing things in the kitchen and spending time searching for them, and loss of practical skills such as cooking, were experienced by Mrs. Peters. Losing track in conversations and having problems expressing oneself coherently frustrated Mrs. Martin and this is another experience commonly encountered with cognitive loss (Steeman, Dierck de Casterlé, Godderis, & Grypdonck, 2006). As a response in these common situations, people with dementia struggle to adjust to the changes dementia produce using self-protective strategies (Steeman et al., 2006). These strategies included normalizing perceived changes as part of aging, focusing on contentment with the way life was going; using medication; becoming argumentative (as

was the situation with Mr. Gladstone); using external memory aids such as calendars, lists, notes (as was the strategy used by Mrs. Campbell); maintaining hope; and relying their partner. These self-protecting strategies aimed to protect the individual's identity and maintain continuity with their identity prior to the onset of dementia. Clare (2002) suggests that to come to terms with dementia it is important for people to balance the despair that results with the threat of dementia, with hope and struggle to acceptance. Although adjusting was difficult for all couples they integrated strategies with a positive attitudes that made the best of a bad situation. Finding out more information about dementia was a strategy all couples used. Mrs. Gladstone attended an Alzheimer's support group.

The couples remained resilient in the presence of dementia. A joint perspective of making sense of dementia and then adjusting to loss during the early stages of dementia created a shared sense of identity related to dementia, but not the whole identity of the couple in-relationship.

4. Marriage means forgiveness

"*She has forgiven me many time.*" (Mr. Martin)

Forgiveness is crucial to healthy marriages. Studies reporting on couples with long-term successful marriages identified forgiveness as one of the top three qualities responsible for their marital success (Worthington, Lerner, & Sharp, 2005). Forgiveness gives people a way to deal constructively with the almost inevitable disappointments that will occur in any relationship and thus heal the emotional bond. Worthington et al. (2005) suggest marital success is not most importantly about how partners behave with each other, but is about the emotional bond between the couple and healing threats to that bond

(p. 261). Although definitions of forgiveness have varied in the research literature, the field is moving closer to a consensual definition of forgiveness. Common to most definitions is the idea of a change whereby one becomes less motivated to think, feel, and behave negatively (e.g., retaliate, withdraw) in regard to the offender. Forgiveness is not something to which the offender is entitled, but is granted nonetheless, leading scholars to describe it as an altruistic gift or the cancellation of a debt (Fincham, Hall, & Beach, 2006)The Martins' story of forgiveness illuminates how they continue to heal their emotional bond. I had asked the couple about the strengths and difficulties in their marriage to which they said:

Mrs. Martin: (laughing) Sometimes that he's nice and sometimes he's not.

Mr. Martin: Sorts of variety.

J: Okay. Is that normal?

Mrs. Martin: Yeah, I guess so. No, I think we fit together quite nicely. If he thinks he's right and I think I'm right, well we are...

Mr. Martin: I always give in.

Mrs. Martin: Yeah sure. Okay. It's a balance and we've, at least I look at it, well if I want to be okay between us, then I just have to make sure that nothing goes between us and he does the same thing, you know. We don't go to bed with a bad attitude, you know.

This was a very interesting comment by Mrs. Martin and reflected a great deal of personal emotion and insight into her marriage relationship. She was not able to articulate her thoughts this well in response to most of the questions I asked. In the following Mr. Martin explains how forgiveness was enacted in the couple's marriage relationship:

Mr. Martin: I think what my mom said often, she says, in a marriage you make sure by the time the sun sets, if something has happened during the day that maybe you were cross or you did something, you apologize and ask for forgiveness and if the other person, you partner, is of the same opinion, even so it hurt her, she will forgive you. Then you sleep over it and the next day is a new day. So you wipe out the old day, there were

difficulties, and you start with a new outlook of thinking about the good things we have instead of maybe sometimes an argument you have. Now people need that, and I've noticed that people that don't argue, I was sometimes amazed, but then I found out there is maybe not enough depth to it. I was just visiting, and she gave me the permission to go and visit my friend in Seattle, his 62nd birthday. I was invited by their sons. They were separated and while they were separated or divorced, the son lived with us for, I think, two summers, and he loved the way our family operated, so he wanted me to come there. He's established himself now, wonderful wife, wonderful kids, and that's what he admired is the steadiness of things that if you have an argument, or different opinion, you discuss it and say this is my opinion. But the other person has to have, they have their opinion, and that will be it, you know. You don't force anybody to believe what you believe, so I think from that point of view, the commitment to each other was there, there's also some tolerance, and she had to be able to do it because I was a high energetic driving force that sometimes it's not easy to live with. So I accept that, I admit that. So she has forgiven me many times.

The Martins had a ritual of not going to sleep until they apologized for differences of opinion or an argument. Hargrave (1994) believes rituals are extremely helpful in the effort to accomplish the overt act of forgiving. Mr. Martin relates forgivenesss to commitment, and in the research literature on the current status of forgiveness in marriage (Fincham, Hall, & Beach, 2006), it has been postulated that the two constructs of forgiveness and commitment are positively related. McCullough et al. (cited in Fincham et al. 2006, p. 419) found partners who report great satisfaction and commitment express higher levels of forgiveness within their romantic relationship. In the Martins' context, self-forgiveness played an important role in maintaining connectedness as the couple had to deal with the fact that they each behaved in a way that was hurtful to the other partner. Mr. Martin also believed in the sanctification of marriage with the view that marriage was a manifestation of God, as he reports "*the first commandment is, does say, love. That's what it says in the Bible. That's how we were raised. Love is the first commandment.*"

The construct of sanctification has been put forth in marital research as the process whereby an aspect of life is perceived by people as having divine character and

significance and religiousness in context. Mr. Martin believed marriage was a manifestation of God and thus had sacred qualities. Mahoney, Pargament, and colleagues' research on sanctification in marriage propose religion has the apparent potential to help couples build marital intimacy, stimulate companionship, and perhaps offer unique cognitive and behavioural resources for couples dealing with marital stressors (cited in Finchman, Stanley, & Beach, 2007, p. 281). Religion was significant to the Peters. Mrs. Peters believed that a faith community could offer better support for them as a couple now that she had "fallen over." In describing why they had decided to move back to a small community, close to their son who was a minister, and to a supportive community, she refered to the Bible, as follows:

J: Because religion is a large part of your life, how do you think it impacts?

Mr. Peters: Well, I think it does. I think it does, helping your fellow men.

Mrs. Peters: You can use a verse from scripture, if you don't help the guy that's along the side, your brother has fallen, if you don't lift him, you know, like the prodigal son, or whatever you read in the Bible, we don't, God doesn't like that. He likes you to help these poor guys down in the gutter, or whatever, who have fallen over. I mean, if you can help, I think a person should. That's the way it works. That's what the Bible tells us.

Mr. Peters went on to say that he sees the need to help in his neighbourhood. Because several of his neighbours don't mow their lawns, which makes his property look bad he went and mowed four of five lawns all in one section - "*Nobody's mowing lawns, you know, and it looks*".... "*Terrible*" Mrs. Peters then remarked. The Peters also talked about the significance of commitment and forgiveness. At the end of the interview, I asked if there was anything they wanted to add to the meaning of commitment. The Peters responded in this way:

Mrs. Peters: I think one thing that's very important is the fact not to harp if they make a mistake. We'll say that can happen, like their spouse made a mistake that should never

really happened. I think that, and if we decide we're gonna stay together, if we had a fight like that, I'm just saying. I don't think they should harp on it. Just sort of put it behind them and just keep going. You know, we'll say that one had an affair, well put it that way, and that would, to me that would really blister a marriage. That trust thing is gone, and but then not dwell on it, if you're willing to accept forgiveness that comes through and the promises that they make, take that to heart, I think then don't give up on it, just keep going.

Mr. Peters: Absolutely, and the other thing...

Mrs. Peters: Just keep going. It'll be a big mark across the one spot but from there get together again and just keep going.

Mr. Peters: You have to continue if you want your marriage to last. You have to...

Mrs. Peters: And especially if there are children involved.

J: Was this you? Or are you talking about other people?

Mrs. Peters: No, I think for anybody else. This is the way I would feel if that happened to us, and for the kids' sake I would do anything that wouldn't break their little hearts, because I seen too much when parents separate and the kids.

For the Peters, forgiveness came via the wedding vows and promises made at that time of their marriage. The vows were "*taken to heart*" which meant you don't give up on marriage. You work through the difficulties, a theme common to all couples as reported in Chapter 5, with the exception of the Gladstones. Although they had worked through the difficulties in their own way, Mrs. Gladstone had a problem forgiving her husband for constantly moving in the early years of marriage, not purchasing her dream home, and the eventual, "*the whopper'*, which was the need to euthanize their beloved dog after he bit a neighbour's dog while Mr. Gladstone was in charge. It has been suggested that unresolved transgressions, such as the Gladstones experienced, may spill over into future conflicts and, in turn, impede their resolution, putting a couple at risk for negative downward cycles of interaction (Finchman, Stanley, & Beach, 2007). The couple experienced a downward cycle of interaction now that Mr. Gladstone had been diagnosed

with Alzheimer's disease. However, it is difficult to know how the symptoms of dementia and their past relationship conflict impacted on the present situation. I can only guess that Mrs. Gladstones response to her husband's behavioural outbursts could have been frustrating for both of them. Also, from my experience, it is not always easy to know when the behaviour is a result of the disease process or the existing tension between the couple. I only know that negative behaviour is exacerbated when people with dementia are confronted with a situation they no longer understand.

The significance of forgiveness

Findings from this study support the recent shift to focus on health rather than pathology in researching marriage relationships. Fincham et al. (2007) talk about a new transformative process in marriage, as an emerging trend, with the focus on greater attention to complexity, resilience, and ultimately context, motivation and meaning systems, leading to second order constructs such as forgiveness, commitment, sacrifice, and sanctification (considered system regulators). The authors argue that factors such as commitment, sacrifice, and forgiveness may serve their protective function, in part, by decreasing the influence of negative partner behavior across repetitive cycles (e.g., by reducing tit-for-tat responding) and so dampen the impact of negative partner behaviour on the relationship (p. 284).

The significance of forgiveness is that the couples studied had chosen to forget selected aspects of their lives. They have presented themselves to me in 'purified form' only. Personal issues, disputes, events, etc. have arrived to me at an 'edited' version of their lives together which they are comfortable with and prepared to share with outsiders.

Ironically, the disease they are dealing with continues the process of editing out memories held by one partner, not necessarily the ones both partners would have chosen to remove. The couples have made an image of their spouses and continue to cherish those images. For example, halfway through the interview with the Smiths, Mr. Smith got up from his chair, and seconds later presented me with an large picture of his wife when she was young, probably around the time of their marriage. "*This is a picture of my wife*", he told me. I believe he holds that cherished memory to this day and when he thinks or looks at his wife, her image remains young and beautiful to him, just the way she looked in the picture taken so long ago.

Summary of discussions: Factors contributing to commitment of the marriage relationship and sustained dementia care.

In this section I further compare the commitment factors that I discovered in the data with existing literature on commitment to the marriage relationship and the dementia experience.

In examining the themes of the couples' commitment and understanding of the dementia experience, I summarize in Figure 11, the relational processes which contributed to the couples' enduring commitment to marriage. The concepts or narrative themes–marriage means partnership for life, reciprocity, resilience, and forgiveness are overlapping processes. The belief that "marriage means a partnership for life" was the basic factor that contributed to marriage commitment. The concept of "reciprocity" signified the couple could work together well to make daily important decisions. "Resilience" represented overcoming difficulties and "forgiveness" represented letting go of past discretions.

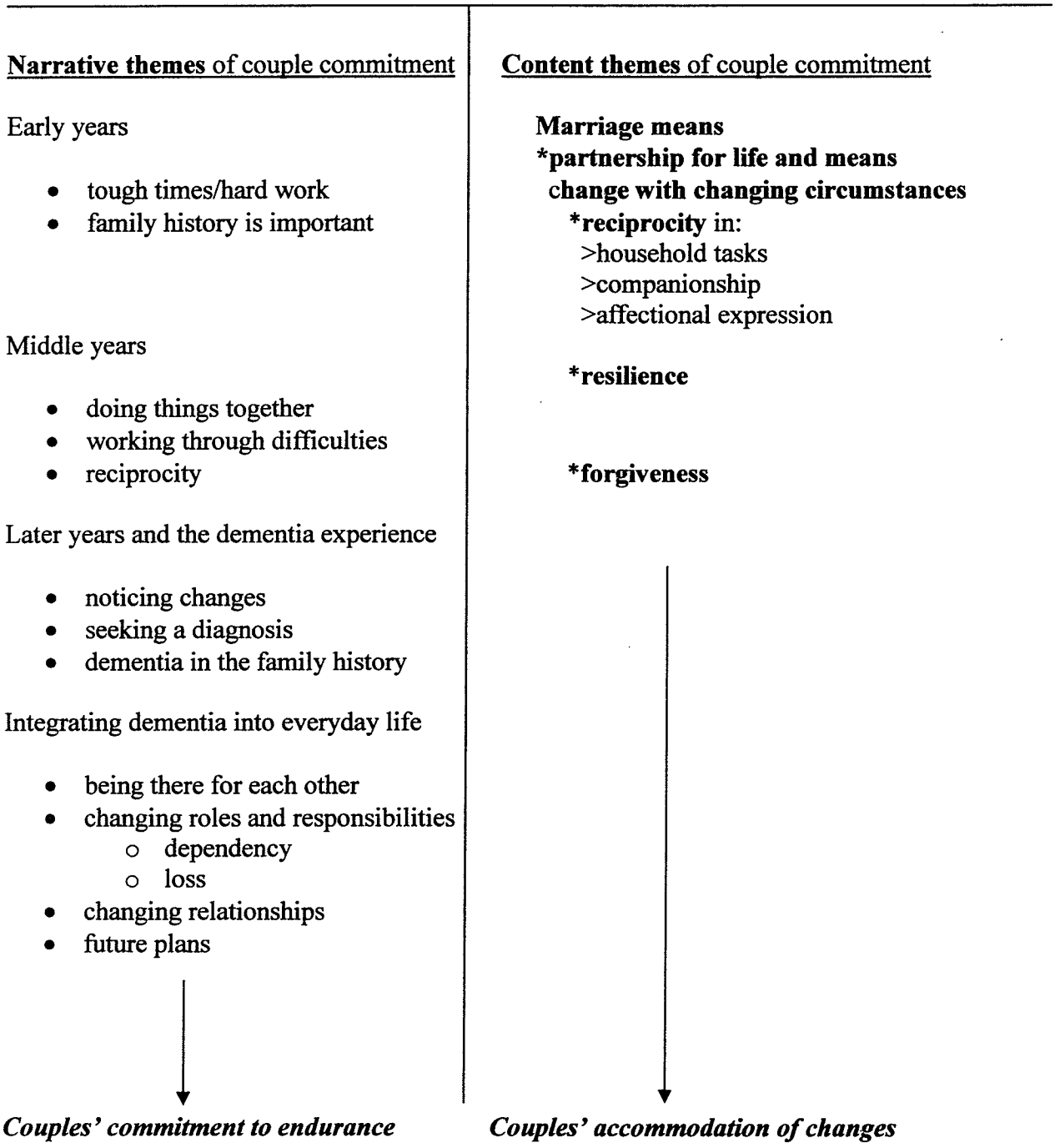

Figure 11: Summary of contributing factors to the marriage relationship to help sustain dementia care

Commitment to the marriage relationship

The literature on commitment to the marriage relationship is limited, and yet, a key characteristic of enduring marriages is reported in the literature as "commitment." In part this can be explained by the fact that until the 1990s, commitment generally remained on the sidelines in clinically-oriented marital research (Finchman et al. 2007). Commitment in the six study couples' marriages was by definition considered a lasting bond between husband and wife pledged during their wedding ceremony before witnesses and God. The marriage bond was considered a binding agreement referring to a promise or obligation to care for each other "in sickness

and in health." Data on the six couples in the study was in agreement with the postulation that caring for a lifelong partner is simply part of the marital bond (Paun, 2003; Perry, 2002) and thus means the couples were able to renegotiate their relationships as changes occurred (Robinson, & Blanton, 1993).

Although Johnson, Caughlin and Hudson (1999) reported three distinct types of commitment - personal, moral and structural, the first two were most significant for research participants. Findings in this study concur with Smedes (1998) who suggests two old-fashioned reasons why commitment to endurance is the guts to commitment in marriage. The first reason is that marriage is for families. The Campbells married because they wanted to have a family. All couples had children early on in their marriages and their children remain close emotionally and in proximity to this day. In fact, in response to the question about what couples believed they would need in the future as dementia progressed, they all agreed the most important resource was and would be the support from their children and grandchildren. The second point that Smedes (1986) made is very significant from the viewpoint of narrative analysis and this study as he suggests: "If we

annul this commitment we fragmentize the stories we are writing with our lives, we let loose of our past and chisel away at who and what we are for the future. We lose a significant part of our identity but what is worse, we rob the other person of the identity that our commitment promised to him or her" (Chapter 5, p. 3). Findings suggest that the *couple's identity* as a couple living in-relationship was **not** lost with the onset of early-stage dementia. In essence each couple still experienced an identity of "**us with a future**", reinforced through the process of **accommodation** of changes (Finchman et al. 2007, p. 280).

The generally agreed upon empirical findings of important elements in long-term marriages were voiced on by the study couples. The empirical findings revealed the five Cs as (1) commitment, (2) caring, (3) communication, (4) conflict and compromise, and (5) expectations both implicit and explicit (Cheung, 2005). Although equality in marriage is currently highly valued in this study, couples remained highly influenced by the institutional model of marriage. They were comfortable fulfilling the traditional roles of breadwinner (husband) and homemaker (wife), although most couples were retired. Had I not asked the questions about commitment, I do not believe the couples would have used the word. It was just taken for granted that the marriage would last. Words like "*staying together though thick or thin*" and "*you do what you said you would do in your wedding vows*" conveyed the pragmatics of the term 'commitment' as endurance, tolerance, and perseverance. Couples indicated that no relationship was without its ups and downs. The trials and tribulations of everyday life were bound to engender tension and upset. However, the willingness to stay together for life, to change with changing circumstances, meant coming together at a deeper level of love after tragedy, such as the Campbells and Martins experienced with the sudden death of a child.

There is no doubt that the results of the study confirm that favourable conditions experienced during childhood in a loving home build up a stable basis of trust form the fundamental prerequisite for a couple's successful relationship with their spouse (Sharlin, Kaslow, & Hammerschmidt, 2000). Mrs. Burns recalled that one of her happiest memories was listening to her parents' discussions over breakfast. Mr. Gladstone's recollection of an unfavourable childhood remained a wedge between him and his wife and was apparent during the interviews.

Understanding the couple in the context of a diagnosis of Alzheimer's dementia

With each couple, a general practitioner (GP) was the first physician to see and assess the study spouses with possible dementia. With the current focus in the research literature on the benefits of early diagnosis, these GPs referred their patients to a memory clinic specializing in diagnosis of memory problems in general and Alzheimer's disease specifically. The study spouses demonstrating signs and symptoms of dementia were all diagnosed as having "probable Alzheimer's disease." Several of the traditional warning signs, such as inability to recognize certain words, use of inappropriate words for communicating, disorientation to time and place, problems with abstract thinking, and difficulty with everyday tasks such as cooking and dressing, were recognized by spouses. The diagnosis was disclosed to spouses as they were all recruited for a clinical drug trial. Although some research suggests level of awareness should be considered when making a decision about when and how to share diagnostic information (Macquarrie, 1995), research supported the work of Harman and Clare (2006), who sugest that couples needed and wanted to know the diagnosis. For the study couples, it meant continuity to the "us identity" in their marriage relationship-biography. Mr. Burns, Mrs. Smith, Mr. Gladstone,

Mrs. Martin, and Mrs. Peters were enlisted in a clinical drug trial for treatment and were prescribed Flurizan (Myriad Pharmaceutical Company). Mrs. Campbell was taking the licensed drug, Exelon. The purpose of the study was to evaluate the changes in cognitive ability and activities of daily living in patients with Alzheimer's disease as measured by specific evaluation during 18 months of dosing. All caregivers in the study played a critical role as they had to ensure their spouse took the medication as prescribed and attended at their follow-up appointments when scheduled. Mr. Smith found the traveling to different sites for specialized tests his wife was required to have very exhausting. He asked me why the assessment services couldn't be located in the same building. The couples were all very optimistic regarding medication and hoped it would stabilize their spouses' symptoms supported in the literature on the same subject (Lindstrom et al., 2006).

As mentioned in Chapter Two, research on the impact of early-stage dementia on the marital relationship is limited. Few studies attempt to combine the perspective of the people with dementia and their partners as this study did. That stated, in the process of analysis, I did find several new and exciting research articles supporting the interactional perspective of couples and the importance of a future focus to relationship centered care in dementia. For example, the findings of this research supports that of Robinson, Clare and Evans (2005), whereby couples described a joint negotiation and adjustment in acknowledging losses. My understanding of the process of joint negotiation and adjustment was that in this current study couples "changed with changing circumstances" throughout their marriage biographies and now were able to "accommodate change" once their spouses were diagnosed with Alzheimer's disease. In the thinking of symbolic interactionism, the study couples created a "*joint production of meaning*" to the dementia

experience. Current research also recognizes resilience and the importance of relationship-centered care in understanding the socio-cultural context of dementia (Clare, & Kirchner, 2006; Mernoij-Dassen et al., 2006; Mahoney, et al., 2005)

People with dementia are experts in their experience

"*My memory is really gone and I just hate it.*" (Mr. Gladstone)

The study spouses with Alzheimer's disease accounted for their difficulties in different ways. Howard and Saper (2003) have suggested subjective themes used by the study spouses. Mrs. Peters experienced frustration, distress, and defensiveness when confronted about her ability to manage meals in the kitchen. Mrs. Martin became very upset when she was no longer able to operate the TV control. Mr. Burns seemed generally unconcerned at an emotional level despite explicit awareness of deficits. Mrs. Campbell normalized the experience, adopting a stoical attitude to her symptoms. For example, she commented, "*I guess I'm getting old.*"

The study spouses with Alzheimer's disease were concerned with the changes they were experiencing and were striving to maintain continuity to their day-to-day activities by trying to do as much as they could (Menne, Kinney, & Wilkinson, 2003). Smyth et al. (2002) claimed that families as a unit could be helped to understand the meaning of dementia in their lives and to learn meaningful roles and relationships early on in the illness despite deficits. The idea that families can be helped to understand the meaning of dementia in their lives in order to be helped is disputable. Care providers need to understand how families understand dementia in their lives. One way to better understand this is to consider the person with dementia as the expert in his or her

experience of dementia, and not consider the helpers or professionals as the experts. One of the unique findings this study adds to the research understanding of dementia is that, although dementia impacts on the marriage relationship, there is a far greater influence of the marriage-relationship itself on the dementia experience. The study couples had developed resources for accommodating change throughout their married lives. Their belief in marriage as a partnership for life, in reciprocity, in resilience, and their capacity to forgive and let go of past transgressions created a strong healthy "us identity" contributing to their ability to sustain dementia care in the early-stages of the Alzheimer disease process.

Carers are experts in their situation

The study caregivers were experienced. They all acquired their skill and expertise by trial and error, had a good grasp on their situation, and were experts in their situations (Nolan, et al, 1996). One of the consistent findings from a large longitudinal study by Gaugler, Zarit, and Pearlin (2003), focusing on 'carers as experts', was that caregivers who experienced a less abrupt transition to care (e.g., over a longer period of time) prior to diagnosis were less likely to place their relatives in institutions or experience poor adaptation over time. The study caregivers were well entrenched in their responsibilities prior to the professional diagnosis of Alzheimer's disease. This is an interesting point as four of the six couples said they wanted to "hang in at home" as long as they could. Mr. Campbell and Mr. Martin claimed they would hire extra help for their wives, at home, down the road, if they needed it. Mr. Smith responded, "*Well, the thing is, I hate to think of it even, but should one of us, something happen, I'm not gonna stay here. She can't stay here, and that is what I'm wondering. Like I said, I never mentioned this to her at*

this point, because it was only this morning I started thinking about it." Even then, Mr. Smith was referring to both he and his wife moving to seniors housing closer to his daughters. As well, the Peters planned a move to the country to be closer to support of their son and his family.

The study findings concur with most of Nolan, Grant and Keady (1996) who found the main adaptive task in chronic illness was to develop new but equally valued roles to replace former ones. The two broad care types they introduced into the research literature were (re)constructed care and reciprocal care. These care types were considered by the authors to have a temporal relationship. The study couples demonstrated (re)constructed care by building on the past to develop new and valued roles. The authors also claim that the purpose of this type of care was to rebuild a new identity on the foundation of past histories and biographies. This claim was not consistent with the current findings. The study couples did not built a new identity, but accommodated changes to their "us identity" that existed prior to the diagnosis of Alzheimer's disease.

The other care type identified by Nolan et al. (1996) was reciprocal care, a major theme identified both in the thematic and content analysis of the couples' narratives. Reciprocal care, according to the authors, refers to opportunities for reciprocal elements in the caregiving relationship that can be viewed from a number of different levels. The authors suggest that reciprocity and satisfaction should be seen as the norm in most caregiving relationships and that these can be sustained even in the face of objectively adverse circumstances. They warn that the absence of reciprocity and satisfaction should act as an indicator of the need for additional support of services. I found the five couples - the Campbells, the Burns, the Martins, the Peters and the Smiths - were able to sustain reciprocal care in early-stage dementia. These couples also scored high on the DAS for

marriage satisfaction. The Gladstones were less able to demonstrate reciprocity and were also less satisfied, as indicated in their DAS score. Reciprocity was sustained for most couples. However, the interesting finding from the data was that couples were still very satisfied with their marriages, all things considered, but mostly unhappy when asked about the degree of happiness, all things considered. The study couples managed to find positive aspects (Butcher, Holkup & Buckwalter, 2001) to the caregiving process as well as meaning. Meaning and joyous times were created through recollection of earlier happier memories, engaging in pleasant activities they could enjoy together, cherishing the preciousness of the immediate moment, and remaining loyal to the commitment to one another, as suggested by Butcher et al., (p. 51).

Facing the future one day at a time

Study couples responded to facing the future with hopeful positive attitudes. They tended to live in the present, as a result of daily fluctuations in dementia symptoms experienced by their spouses. In other words, every day was different and no behaviours were totally predictable from one day to the next. The couples showed a mutual concern for the well-being of each other (Moniz-Cook et al., 2006). Quality of life was experienced in the domain specific areas as conceptualized by Broad, Stewart and Sands (1999) in their D-QoL scale for the person with dementia, and included the following:

- **Asthetics** - relates to enjoying/appreciating nature, beauty and surroundings. Mrs. Campbell loved working in her garden. It was the only place her husband felt confident that she would not try to wander off from. Other couples expressed enjoying a drive in the country.

- **Positive affect** - relates to experiencing humour, feeling happy, cheerful, content and hopeful. The spouses diagnosed with Alzheimer's disease were genuinely happy. They could laugh at themselves and the idiosyncrasies of their personal relationships as they related to me the good and bad times during their long-term marriage relationships. All couples were optimistic that the clinical drug trial medication prescribed would help delay the Alzheimer's disease process. Even though they were aware they may have been prescribed the placebo, they were confident that the future would provide symptom relief in one form or another.
- **Negative affect** - relates experiencing worry, frustration, depression, anxiety, sadness, loneliness, fear, irritability, nervousness, embarrassment and anger. Most of these negative affects were experienced, expressed, or demonstrated during the interviews. Often spouses worried they were a burden to their caregivers, and they became embarrassed with the consequences of failing memory.
- **Self-esteem** - refers to accomplishments, confidence or satisfaction with self, and ability to make decisions. The self-esteem of the spouses with Alzheimer's disease was compromised. They were often no longer able to make their own decisions and needed the supervision and or direction from their spouses to complete tasks.
- **Feeling of belonging** - related to feeling lovable, liked, and useful. I believe the spouses with Alzheimer's disease felt loved by their spouses. They were still able to feel useful around the home with most of them participating in household chores.

The D-QoL measures quality-of-life related to person-centered care. The current research and experience supports the current thinking based on the groundbreaking work of Nolan et al (1992) that, although person-centered care has transformed our thinking and to a degree practice in dementia, it does not fully capture the interdependencies and reciprocities that underpin caring relationships.

As stated in **Chapter One, Paradox Four: Despite the current focus on quality of life for both the person with dementia and their caregiver, "the relationship" central to promoting quality of life is missing from much of the literature.** Relationships are central to caregiving as suggested by Forbat, (2003). The current findings support the notion described by Nolan et al (2002) that quality relationships based on mutual respect and regard act as a buffer in providing an enriching dementia experience. In the current, study couples were living-in-relationship and the strength of that relationship created over their long-term marriage created interdependencies and reciprocity resulting from their enduring commitment to their marriage and each other. The relationship acted as an "energy source" to help offset the impact of dementia and sustain the couple in the early stage of Alzheimer's dis-ease. The current study suggests that what is of central importance is to understand the quality and history of the dyadic relationship between the person with dementia and her/his spouse. That relationship influences the quality of life of the person with dementia and the experience of caring as Whitlatch (2001) and Woods (2001) suggest.

The significance of symbolic interactionism to the research study: An assessment

The significance of symbolic interactionism to the research study on marriage commitment and the dementia experience was in the perspective it offered - that human beings are ever-changing actors, communicating, role taking, co-operating, and problem solving along a stream of action. This perspective helped provide an understanding of marriage and how couples perceived, interpreted, and lived out the dementia experience in their lives. The concept of understanding lies beyond perception because it introduces meaning into the situation. Meaning needs to be understood to be appreciated. The purpose of the research study was to understand what the couples themselves believed was the meaning of the dementia experience. What was important from the SI perspective, was that couples were constantly changing and "becoming." The couples' relationships were considered dynamic, and their interactions influenced what they did and who they were. The couples were not as Charon (2004) suggests, damned or blessed with the past as a determining agent, or imprisoned by traits or ideas developed long ago. Charon summarizes it nicely with the following comment: "It is always in the present that we actively define what is important. Interaction with others and with self constantly shifts our direction, our action, our definition of the world and self" (p. 191).

According to SI, the concept of mind plays an important role in the understanding of human beings and the active relationship they have with their environment. Long ago, Mead (1934), linked the concepts of mind, self and society. Mead claims humans with minds and selves create a certain type of society; human society creates a unique being that possess mind and self. Also, mind and self are linked, and everything in turn is linked to symbols.

Mind is considered an active concept involved in the process of thinking, or covert action, such as talking to oneself, engaging in conversations with oneself about the environment.

The self in SI is the object one talks to when engaged in covert action such as talking to oneself. Mead suggests, "The actor acts; the actor acts towards the outside environment; when the actor acts toward the self he or she is engaging in mind action." SI considers individuals in control of their own action in the present- defining thinking, controlling his or her own choices. Thus, the human becomes less passive, moved much less by deterministic forces. Now it is possible to identify ways that human beings take control from their environment (Charon, 2004).

In assessing the findings of the study through the lens of symbolic interactionism I was able to understand that couples were not acted on by the dementia experience but played a key role in its definition to their relationship. The study presented the "joint production of meaning" of the dementia experience with less focus on the self or individual identity. Several researchers, focusing on individual with Alzheimer's disease, believe in the early stages persons with the disease are able to convey concepts of self through communication and interaction (Davies & Gregory, 2007; Li & Orleans (2003) cited in Karner, & Bobbit-Zeher, 2006, p. 553). Karner, and Bobbit-Zeher (2006) suggest that caregiving is a fundamentally different experience for those who have known and cared for the demented person prior to illness. As Mr. Martin remarked, "*This is a different challenge*" (referring to providing care to his wife with Alzheimer's disease). To counteract this threat, family members must re-conceptualize their understanding of dementia symptoms and reconfigure the relationship as one in which the individual will

"keep his place" as a symptomatic, ill person (Goffman, 1971, cited in Karner & Bobbit-Zeher, 2006, p. 553).

The significance of narrative analysis to the research study: An assessment

Tolstoy once posed the prophetic words: "Science is meaningless because it gives no answer to our question, the only question important to us. 'What shall we do and how shall we live'" (p. 143, cited in Frank, 2002). Franks' response to this statement is that through stories people have found present ways of living that include what to do, and how to live. The relationship between life and story is considered interpretive (Mills, 1998) and as narrative is interpretive, representations (Riessman, 1993). Further, Mishler (1991) points out the researcher influences the form and content of the narrative through the process of interaction.

I used the narrative analysis schema developed by Reissman (1993) for the inductive research process that began with the primary experience itself. Couples narrated their stories of primary and daily experiences of commitment to their long-term marriage and the impact of dementia to that experience. I represented their experience, interpreted it with my understanding that I influenced form and content though my interactions with the couples. Thus we became co-creators of the findings.

I next transcribed the conversations from the taped interviews; transcribing which involved representation of the conversation into text, an interpretive process. There were times in the investigation where I was unable to understand the informants' words. I transcribed them in the way they were told to me. In the context of the couples' responses, words did make sense. Most of the narratives were told to me in stories, views, and on occasion, metaphors. There were very few non-lexical utterances. During the

transcription process, I endeavored to impart a sense of coherence to the whole. The thematic analysis reflected the words spoken by the couples, as they attempted to give meaning to their lives.

The final level of representation occurs when the reader encounters the written report of the investigation (reading). The reading of the text, according to Riessman (1993, p. 15), is open to varied interpretations. Reading is considered ambiguous because it is fluid and contextual, an interaction between self, teller, listener, analyst, and reader.

A truthful narrative is one that is faithful to facticities and facts, and creates believable experiences for the reader (Mills, 1998, p. 44). This means being internally coherent, having a continuous structure in which events are logically related to latter occurances, a process I described in Figure 8 of this chapter. Trustworthiness, considered by Riessman to represent the validity of the narrative, moves the process into the social world. An article of the preliminary findings has been accepted by the scientific community as having merit and adding to dementia research with the publication of an article in *Dementia: The International Journal of Social Research and Practice* for publication 6(4) 2007. I believe the research is strengthened by three types of coherence as described by Agar and Hobb (1982) - global, local and themal - and described throughout the analysis.

A final conceptual model of the understanding of marriage commitment on the dementia experience

On the basis of my conceptualization of findings in Chapter Five to Chapter Eight, I reformulated a conceptual model to illuminate the enactment of commitment to the marriage relationship to help sustain dementia care. Figure 12 is a synthesis of: (1)

Figure 6, the original conceptual framework of preliminary findings of the understanding of commitment to the marriage relationship on the dementia experience; (2) Figure 8, the influences in the commitment cycle, the contributing factors summarized in Figure 11, as summarized in this chapter. Since the model does not attempt to explain a causal relationship among factors, I used arrows to indicate influences and the interconnection of dyadic-level influence between identified factors. The bold factors represent significant new knowledge that I add to the existing knowledge on commitment in marriage and dementia studies.

The significance of family history and culture on marriage

It can be seen that the framework in Figure 12 begins by acknowledging the influence of family history, and socio-cultural expectations, and experiences of marriage. These factors are meant to capture the role of the larger context within which dyadic influences are often embedded. The couples' relationships in marriage were structured by social understandings and shared perspectives of their culture. Couples continued to interact and agreed to use the culture to guide what they believed and did. This led to ongoing cooperative interaction. The family lifestyle and structure represented by the 1950s provided a backdrop to understanding the social and cultural ideologies reflected in the couples' marriages. This backdrop provided an understanding of the rules, values and norms that influenced decisions made by couples and what was important to pass on from one generation to the next.

The significance of commitment on marriage

The newer element of this model is its focus on the role of commitment and the major factor affecting it, a couple's enduring personal commitment. Figure 12 suggests that satisfactory relationship biographies influence positive dyadic interactions linking a

couple's belief in marriage to patterns of care as enacted through a partnership for life, reciprocity, resilience, and forgiveness. These factors help sustain dementia care as they result in a high likelihood of a couple's capacity to change with changing circumstances. The dementia experience signifies a significant challenge to the couple's relationship with changing roles and responsibilities following. Each spouse was deemed either a caregiver or a patient with the formal diagnosis of Alzheimer's disease. Each couple emerged secure in their relationship and mutually trusting. The couple's relationship functioned differently than it did before the couple overcame the challenge of dementia together and accommodated the changes within the relationship itself. Quality of life meant facing the future one day at a time, with the focus on living in the present. Although the couples were living with the experience of dementia in the present, all spouses maintained their enduring commitment to each other. In other words, **they were committed to the 'future of us' one day at a time**. The framework captures insights from symbolic interaction and the interactional process of meaning making. The framework would seem to have considerable potential to help us to better understand commitment in marriage and how it impacts on couples facing the challenge of Alzheimer's disease in the early stages.

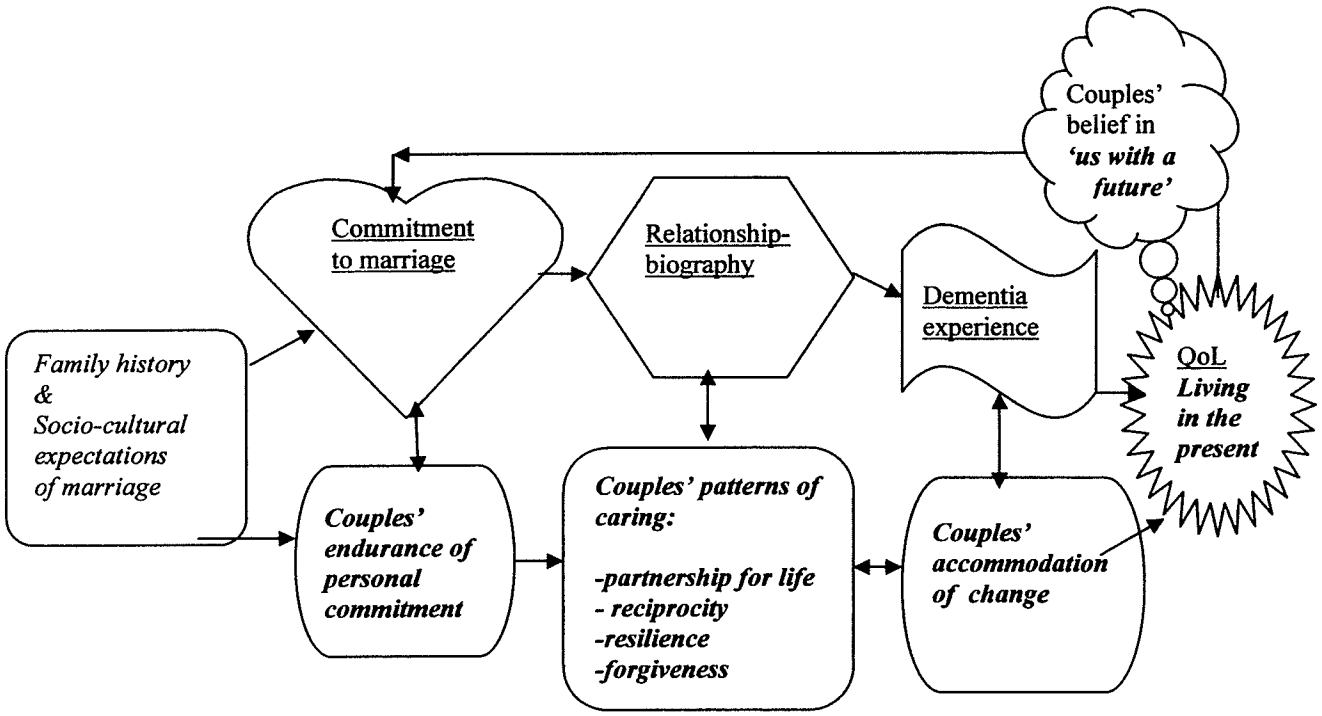

Figure 12: A final model of the understanding of commitment to the marriage relationship on the dementia experience

Rethinking the meaning of marriage commitment and dementia as identified in the research questions

The marriage commitment provided a structural foundation for a couple's relationship. Their shared purpose was the means by which they stabilized their marriage and this shared purpose was unchanged by circumstances throughout their married life. They understood the symbols, signs, and patterns of interaction in their marriage long past the ability to articulate them. It is only when a couple had different goals that perception shifted, meanings changed and shared symbols became confused. The spouses

diagnosed with Alzheimer's disease had a changelessness experienced by both spouses in spite of the diagnosis. The "*us identity of the couple*" changed but remained intact. Couples considered the challenge of dementia to be a "collaborative venture"- a journey into the unknown.

The interpretation of the marital commitment shaped the marital relationship. Commitment was interpreted by the couples as personal dedication and couples maintained or improved their relationship for the joint benefit of each other. Their personal commitment was experienced as wanting to continue because of love for their partner, and they were satisfied with their marriage and couple identity (Johnson, Caughlin & Huston, 1999). Commitment was shaped by the social and cultural values implicit and explicit in the expectations of marriage from a traditional and institutional point of view reflective of the 1950s and early 1960s.

The quality, history, and nature of the marital relationship-biography constructed over the couple's lives together helped explain their current relationship. The couple's two histories were seen as "interacting story lines rather than separate narratives" as Forbat (2004 p. 81) suggested, and Mr. Campbell reiterated in his statement, "*Well, we're gonna hang in here as long as we can. It's as simple as that.*" The spouses took turns as they responded to the interview questions. This demonstrated to me they really were partners doing things together, as narrative themes revealed in the analysis. The significance of considering the marital dyad as living-in-relationship was a marker of their commitment to each other through their marriage, in sickness and in health. As well, the relationship was a marker of the strengths and difficulties in dealing with life challenges and to ascertain the capacity to care. The Campbells and Martins demonstrated tremendous resilience as their death of a child showed. They did not hold

the other spouse responsible for neglect in any way, but assumed the burden of loss together, although the pain was clearly evident as they recounted their story of the tragedies. Each couple's belief in marriage as a partnership for life, that marriage meant reciprocity, resilience, and forgiveness was based, on their enduring commitment to living-in-relationship.

The couples' caring relationship was lived and responded to prior to a dementia diagnosis as mostly *caring about* the other person during times of illness with the narrative theme of *being there for each other* prominent. After a diagnosis of dementia, *caring for* became the focus as the spouse designated as the care giver was now in charge of giving care, literally. Mrs. Gladstone described this experience as "*mothering*" her husband.

Couples reappraised and reconstructed meaning through change in the marriage relationship, roles and responsibilities, after a diagnosis of dementia. This was managed by the couples as accommodating change, a self-maintaining response, integrating it into their identity thus maintaining their "us identity." Harman and Clare (2006) suggest self-maintaining responses tend to accompany the view that the difficulties are part of normal aging. Although dementia is not considered part of normal aging, four of the six couples had experience with family members with dementia of the Alzheimer's type. Thus for some families, it was normal to experience dementia in later life.

The anticipated care requirements needed for the future were unknown by all of the couples. The couples lived day-to-day experiencing the present. The only thing they all agreed on was that they wanted to move or be close to their children and grandchildren for ongoing support.

Summary of unique contributions of the study

The findings, through narrative analysis of the couples' stories, pointed to a number of interesting understandings of marriage commitment and the marriage dementia experience expressed throughout this chapter.

1. Lifetime commitment to marriage suggests commitment was the essence of long-term relationships and helped couples sustain their marital relationships during tough times and a diagnosis of Alzheimer's disease. With the passing of time, husbands and wives increasingly valued each other as unique persons and were highly committed to the future of their relationship.
2. Couples did not undergo a decline in their reciprocal caring relationship as a result of dementia. Spouses strived to maintain continuity to their lives and make meaning of the situation by trying to let the spouse with dementia do as much as he or she could under their spouse's supervision. This fits with the notion of "constructed reciprocity" where spouses were committed to an ongoing loving relationship with their partners viewing them as unique persons despite the cognitive impairment.
3. Most couples reported a continued caring relationship with "undisturbed commitment" and resilience to the changes experienced as a result of early-stage dementia, thus maintaining continuity to the marriage relationship.
4. Forgiveness gave the couples a way of constructively dealing with the disappointments and difficulties and thus be able to heal their emotional bond. The significance of forgiveness is that couples chose to forget selected aspects of their lives to share with me. They presented themselves in "purified form only."

Personal issues, disputes, events etc., arrived to me as an 'edited' version of lives together which they were comfortable with and prepared to share with me.

5. Couple identity, as a couple living-in-relationship, was not lost with the onset of early stage dementia. In essence the couple still experienced an "us with a future identity" reinforced through the process of accommodation of changes.
6. Favorable conditions experienced during childhood in a loving home built up a stable basis for trust in each couple's marriage.
7. Couples changed with changing circumstances throughout their marriage biographies and now were able to accommodate change and joint production of meaning to the dementia experience.
8. Study couples were able to respond to the future with hopeful positive attitudes. They tended to live in the present, as a result of daily fluctuations in dementia symptoms experienced by their spouses.
9. The anticipated care requirements needed for the future were unknown by all the couples. The only thing they all agreed on was they wanted to move or be close to their children and grandchildren for ongoing support.

Summary

In this chapter I processed the narrative material of the couples' stories analytically into content categories relevant to the contributing factors to commitment in marriage that helped sustain dementia care. The categories expanded on the themes and plots from thematic analysis in Chapter Five to Chapter Seven. I presented and elaborated on the findings of four factors of importance that contributed to commitment in marriage and helped sustain dementia care; partnership for life, reciprocity, resilience and

forgiveness. I then compared the findings to previous research, and commented on the significance of symbolic interactionism and narrative analysis to the current research study. Next, I reformulated the conceptual model of the co-construction of marriage commitment on the dementia experience. Lastly, I commented on rethinking of commitment related to the research questions in Chapter One.

Chapter Nine

Conclusion: Theoretical reflections and implications of the study

In this last chapter, I present my concluding remarks about the four patterns of caring related to commitment to the marriage relationships that helped sustain dementia care: (1) partnership for life, (2) reciprocity, (3) resilience, (4) forgiveness. Secondly, I re-examine the concept of commitment in marriage and dementia. Then I discuss the study's limitations and challenges. Finally, I identify the contributions of the study and implications for future research studies in marriage and dementia and clinical social work practice.

Marriage commitment among the couples

1. *Couple partnership*

In this theoretical abstraction, partnership for life not only referred to the idea that marriage is forever "*for better for worse, in sickness and in health, till death do us part*", but that relationships change with changing circumstances. As conceptualized in the theoretical model (Figure 12. p. 266) couples co-constructed their male and female roles in the marriage relationship according to socio–cultural expectations and family of origin patterns of interaction. The couple living-in-relationship, and being totally committed to that relationship, was the vehicle for receiving a diagnosis of Alzheimer's disease and a testimony to the promise they made to each other to be there "*through thick and thin*", "in sickness and in health." Fincham et al. (2007) might describe this process as a "self-regulatory" mechanism located within the dyad that provide the average couple with ways to forge deeper connection or to effect repairs of the relationship after experiencing

distance and frustration (p.278). Self-regulatory mechanisms, such as reciprocity and forgiveness, enabled couples experiencing early-stage dementia to accommodate change in their marital relationships and integrate dementia into everyday life. Katsuno (2005) found through QLI (Quality of Life Index) scores that people with early-stage dementia perceive their current lives as good, and that participants were as satisfied with their lives as the general population. The findings from the high marital satisfaction DAS scores of couples are similar to findings from Kutsuno (2005).

Participants' difficulty in judging the seriousness of their memory impairment is mirrored by the gradual process of diagnosis (Langdon, Eagle, & Warner, 2007) and the insidious nature of the disease itself. All research participants experienced symptoms for at least two years prior to a formal diagnosis of Alzheimer's disease. Mr. Burns and Mrs. Campbell interpreted the cause of memory loss as normal aging and Mr. Gladstone as just getting older even after they received a diagnosis of Alzheimer's disease. In concordance with Clare (2003), research participants demonstrated they were aware of the impact and implications of their memory problems, but in explaining these they tended to seek to 'normalize' the changes as part of normal aging. Research participants, such as Mrs. Peters, were quite capable of expressing opinions about dementia as has been demonstrated in other studies (Clare, 2003; Daniels, Lamson, & Hodgson, 2007; Langdon, 2006). Mrs. Martin and Mrs. Peters were very sensitive to their diagnosis and were well aware of how others responded to them. Mrs. Burns and Mr. Campbell were keen for people to react to their spouses with dementia genuinely, and respond to them as normally as possible.

In line with Goffman (1971), the individuals diagnosed with Alzheimer's disease in the study retained social identity and personal identity. Goffman states that individuals

are linked to society through their memberships in collectivities and their ties to other individuals through social relationships. Social identity is defined as the broad social categories to which an individual can belong and be seen as belonging; age, sex, class, etc. Personal identity, he continues, refers to the "unique organic continuity imputed to each individual, this is established through distinguishing marks such as name and appearance, and elaborated by means of knowledge about biography and social attributes – the knowledge of which comes to be organized around his distinguishing marks" (Goffman, 1971, cited in Karner & Bobbitt-Zeher, 2006, p. 557). What this means is that individuals with Alzheimer's disease are still members of the broad social category of age, class, sex, etc., and still retain their appearance and name. This argument supports the findings in the current study and similar findings from Karner and Bobbott-Zeher (2006) that biography and social attributes exist whether or not the individual remembers their lives and continue to manifest their social attributes. Conceptually, therefore, we are left with individuals who suffer from decreasing intellectual capacity for selfness (or can be seen as enselfed) but who retains his or her social and personal identity (p. 557). This is important to understand because it helps explain how the "us identity" of the marriage relationship-biography moves forward into the future and how that identity is characterized and preserved by the research couples.

2. *Couple reciprocity*

Reciprocity, the bidirectional exchange of resources, is a dimension of support that is important in the caregiver's ability to sustain supportive relationships while providing care (Neufeld, Harrison & Neufeld, 1998). Equity theory according to Gouldner (1960) suggests when there is no perceived opportunity to reciprocate social support individuals may experience indebtedness and be less comfortable in the

relationship. As well, inability to reciprocate or respond supportively can lead to perceptions of loss of dependence, diminished self-worth, anger and guilt (cited in Neufeld et al., 1998, p. 960). In this study taking on the caregiver role in early stage dementia meant taking on new responsibilities, primarily decision-making and supervision, and care. The former give-and-take relationship between the couples began to change. Taking on the role of being cared for in early stage dementia meant loss of former responsibilities related to decision-making. The cared for now supervised for routine day-to-day tasks such as preparing meals or managing finances. The study couples with the exception of the Gladstones maintained their reciprocal relationship in areas of household tasks, companionship, affectional expression as indicated in their DAS scores.

There are two variations between reciprocity in relationships according to Neufeld et al., (1998), the pattern of social exchange (a mutually gratifying pattern of interaction between individuals of similar status) and reciprocity as a general moral norm (a belief that one is morally obligated to return what has been received). The authors claim this distinction facilitated differentiation of *waived* and *generalized reciprocity* from *constructed reciprocity* in their study of men as caregivers to cognitively impaired wives. Waived reciprocity refers to reciprocity when expectations of immediate reciprocity are relinquished and an open-ended time period is used in assessing reciprocity. Generalized reciprocity refers to an expectation that assistance received will be returned to an individual other than the original provider of support. Constructed reciprocity is a special form of reciprocity that develops in the presence of confused and ambiguous communication. Neufeld et al. (1998) found male caregivers of spouses with cognitive impairment used observation to monitor their interaction with their impaired spouses and

to attend to non-verbal behaviors. Subtle and indistinct non-verbal behaviors were described as a form of responsive interaction.

The findings of this current study lend support as both Mr. Martin and Mr. Campbell attended to non-verbal behaviour of their wives and therefore demonstrated constructed reciprocity. For example, Mr. Campbell watched his wife's behaviours when he worried she would start to wander. He was relieved to be able to attend to her non-verbal behaviour and communicated by diverting her attention from wandering, or planning a "wandering activity" such as a trip to the mailbox to mail a letter. Mr. Martin also provided an example of constructed reciprocity in his narrative by interpreting his wife's frustration in not being able to articulate what upset her when she was left alone in the home for the few hours that he is at work during the day. He would leave a short list of simple activity tasks, for her to refer to and feel useful, such as get the shrimp from the freezer. When she was unable to communicate as to what was frustrating her, for example, in the situation where she was unable to turn off the TV to watch the Oprah show, he went home from work immediately and turned the program on for her to watch. A previous study by Neufeld and Harrison (1995), found that women caregivers interacted with constructed reciprocity when the care recipients had limited ability to reciprocate. In my study husbands being cared for by their wives were mostly able to communicate their needs, carry on a conversation, and reciprocate support.

3. *Couple resilience*

In a study of resilience and family caregiving for a person with Alzheimer's disease, Ross, Holliman, and Dixon (2003) identified caregivers as 're-silient' in that

they discovered methods of dealing successfully with the demands of caregiving. Methods were discovered by caregivers to accommodate change and this was the reason they found no need to seek out services or ask for outside advice. It was only when Mrs. Gladstone was no longer able to accommodate Mr. Gladstone's angry outburst that she phoned her doctor for help.

Resilience strengthens the marital bond according to John Bayley (cited in Garner, 1999) who wrote a love story, "Elegy for Iris", a testimonial to devotion, and an honest account of the challenges and rewards of providing care to his wife of 43 years who died from Alzheimer's disease in 1999. He wrote that there was a certain irony that after 40 years of taking marriage for granted, marriage decided it was tired of that and took a new hand in the game. "Purposefully, persistently, involuntarily, our marriage is getting somewhere. It is giving us a choice, I am glad of that" (Garner, 1999). This comment supports my belief that marriage relationships impact the dementia experience to a greater degree than has been considered in the research literature. For example, a recent study by Potgieter and Heyns (2007), on the stressors and strengths of caring for a spouse with Alzheimer's disease, adds to the body of literature, and Paradox 2, referred to in Chapter 1: Despite research claims of burden, stress, and difficulty coping with dementia families still prefer to care at home for as long as possible. These authors the reported that the group of caregivers involved in this analysis of stressors and strengths presented with a relatively high degree of carer burden, anxiety and insomnia. In spite of these stressors, however, caregivers were shown to have the ability to maintain a measure of life satisfaction, as indicated in their scores on the SOC (Sense of Coherence Scale) compared to the average score from a meta-analysis of a number of South African surveys of different groups. Potgieter and Heynes (2007) findings support the belief in

couple resiliency found in the current study. Qualitative data indicated that caregivers were engaged on a daily basis in a process of preserving the comprehensibility, manageability and meaningfulness they could ascribe to their lives, showing greater strength in the face of stress than is usually recognized (p. 561).

Couples in the current study demonstrated a number of strengths which were shown to contribute significantly to their sense of coherence. Factors such as the maintenance of a partnership, reciprocity, resilience, and forgiveness directly or indirectly were linked to the couples' sense of coherence. So much of the literature, particularly in the past, did focus on the impact of dementia on the caregiver and more recently on the person diagnosed. There is no doubt that stress and burden result from caregiving. The person with dementia wants to maintain a worthwhile identity. For future consideration an assessment of the marriage relationship-biography, and more specifically commitment to caring, should become a priority in the design of support services for couples experiencing early-stage dementia, not burden and stress. Burden and stress do not accurately predict service needs.

4. *Couple forgiveness*

"*Forgiveness cannot be for one and not the other. Who forgives IS healed. And in his healing lies the proof that he has truly pardoned, and retains no trace of condemnation that he still would hold against himself or any living thing*" (A Course In Miracles p. 625).

One of the emerging trends in the transformative processes in marriage described by Fincham, et al. (2007) is the study of a new construct, *forgiveness.* The authors describe this construct as transformative and a regular component of repair in healthy relationships. They claim the potency of negative events necessitates repair processes that

are fundamentally transformative (p. 279). A recent book by Borris-Dunchunstang (2007) titled Finding Forgiveness, echoes the same sentiments and provides a 7-Step Program for letting go of anger and bitterness. The author maintains that forgiveness is ultimately about *inner healing.*

Mrs. Peters believed it was important to "*accept forgiveness*" related to the promises made in marriage. Mr. Martin claimed "*she forgave me many times*" in their marriage relationship in referring to his wife. Both couples reported a strong Christian faith and made reference to the importance of God in their married lives. The study couples were all married in churches with a traditional Christian services. Spiritual growth, within an increase of faith and a greater closeness to God was reported as one of the greatest gains experienced in the study by Sanders (2005), of strains and gains of caregivers of individuals with Alzheimer's disease. All of the caregivers in the study who reported that gain were of the Christian faith. Many looked at their spiritual growth as the primary mechanism that allowed them to assume the caregiving role, as well as combat its inherent strains. Forgiveness is a central concept in Christian faiths.

Religious conviction played a particularly prominent role in ensuring the continued health functioning of caregivers in the recent study by Potgieter and Heyns (2007). The surrender to a 'Higher Hand' brought much relief and restored a sense of manageability to caregivers experiencing feelings of loss of control in caring for their husbands with Alzheimer's disease (p. 560).

Commitment in marriage and dementia – 'us with a future'

The central distinction in commitment research is between commitment as an intrinsic desire to be with a partner in the future, referred to as dedication or personal

commitment, and commitment defined in terms of limits on personal choice referred to as constraint commitment (Finchman, et al., 2007). Mr. Peters' comment, "*Commitment, it means dedication*", and Mrs. Peters response, "*Through thick or thin you hang in there*", reflect the notion of us with a future. Mr. Campbell's response to caring for his wife with dementia was, "*If it were the other way around, (*Ada) *would be caring for me*" Mr. Martin believed how you cared for each other was a true test of marriage commitment. Levinger (1979) suggested long ago that commitment to a future together has the effect of transforming two individuals into an *us* (cited in Finchman et al., 2007, p. 280). Couples' belief in hope for relief of the symptoms of Alzheimer disease and delay of the progress of the disease, was demonstrated in their participation in a clinical drug trial.

Relationships matter in dementia caregiving (Lewis, Hepburn, Narayan, & Kirk , 2005; Lyons, Zarit, Sayer, & Whitlatch, 2002). Symbolic interaction posits that to truly understand a situation, it must be considered from both an observer's perspective and the perspective of the actor involved in the situation. The spouses were the actors in the current study, and I took the observer perspective as the researcher. Agar and Hobbs (1982) reflect on interpreting coherence in discourse and suggest it is often difficult to know how much of what is said is a reflection of the culture, how much is the speaker's interpretation, and how much is due to the interview situation itself (p. 1). All three were involved and interrelated in the final analysis of how relationships matter in the couples narratives.

Relationship mattered to couples, and it was reflected in their beliefs and goals that marriage meant a partnership for life, reciprocity, resilience, and forgiveness. Couples worked at their marriages to maintain their "us" identity and were faithful to their wedding vows. The analysis of the respondents' narratives demonstrated global,

local, and themal coherence. The global theme *marriage is a partnership for life* reflects the respondents' commitment to marriage. Local themes, such as *working through difficulties, doing things together*, and *being there for each other*, represent a bottom-up view which was generated from the core narrative of the narrator's story. Themal coherence was represented in the unifying themes of the text: *partnership, reciprocity, resilience, forgiveness*, and the respondents' cultural assumptions and beliefs about marriage.

Although the diagnosis of Alzheimer's disease impacted the couples' sense of coherence there remained a sense of meaning to their situation. Couples perceived the caregiving situation as comprehensible, manageable, and meaningful (elements of Antonovsky's Salutogenesis theory). Couples experienced the time before a formal diagnosis of Alzheimer's disease, when their spouses' behaviour were characterized as bizarre and incomprehensible, the most difficult period of caregiving (Potgieter & Heyns, 2007). The manageability component of a person's sense of coherence refers to the confidence that a person has that resources are available to manage difficult situations successfully. Study participants had the support of ongoing care and education on Alzheimer's disease from the monthly visits to the memory clinic. During their appointments, both the clinic nurse and neurologist responsible for monitoring the clinical drug the couples were under study for assessed their personal and home situation and answered any questions they had. In that way couples had confidence they would be able to manage the situation successfully.

How couples manage care has recently been studied as a follow-up on family functioning one year after participating in a research project by Heru and Ryan (2006). After one year, the caregivers who stayed in the project reported no change in burden,

reward, quality of life, or overall family functioning, although the patients' activities of daily living and level of disability were perceived to have significantly deteriorated. Findings also suggested that caregivers who had reported poor family functioning at initial assessment had higher ratings of strain and burden. These findings suggested that the "wear and tear" and the "stress process" models of caregiving may not be the only models of caregiving. Perceived rewards can be the main driving force behind caregiving and burden or strain, and poor family functioning could be a factor that modifies a good caregiving experience (p. 229). This is an interesting finding and supports the theory that after diagnosis, couples use the resources built up over a lifetime of caring and adapting to change and accommodate the experience of dementia into every day life – at least in the early stages of Alzheimer's disease. The spouse diagnosed with dementia tries to do as much as he/she can (Menne, Kinney, & Morhardt, 2002), and couples maintain involvement with each other by doing things together (Hellstrom, Nolan, & Lundh, 2005) as they had in the past.

Analysis of the talk of people with dementia and their spouses can make a valuable contribution to understanding care relationships (Forbat, 2003), that personal faith in God is associated with the couples' perceived quality of life (Katsuno, 2003), and that couples stay together "till death do us part" (Lobo-Pravhu, Molinari, Arlinghaus, Barr, & Lomax, J. (2005) by holding on to the familiar, reaching out for emotional support, and commitment (p. 161).

Contributions of the study: What have I added to the existing knowledge on the study of commitment to the marriage relationship on the dementia experience?

"*LOVE is of the mind, in relationships, and not in the body.*" (Study author)

The study of marriage commitment and the dementia experience brings new dimensions to a relationship-centered approach to dementia care generally (Nolan, Davies, Brown, Keady & Nolan, 2004), and commitment to the marital relationship on the dementia experience specifically. It contributes to our understanding of how couples live with early stage Alzheimer's disease. It takes the position that carers are experts in his or her situation and the person with dementia is an expert in their own experience and expands on that. The current study considered the couple living-in-relationship as the experts. What is significant is that the study focuses on the couple's relationship and how that has an impact on the dementia experience, not the reverse. The dementia experience and its impact on the couple has served as the central tenant in most research over the past several decades. This contribution is new and distinctive. This inclusive vision has potential for the future of dementia care practice, policy and research. The current study contributes to dementia care theory and knowledge about the impact of the marital biography in early stage dementia. By employing commitment as the organizing principle, the theoretical formulation contributes to a significant and deeper understanding of how couples work through their relationship in the midst of a diagnosis of Alzheimer's disease.

The existing literature on marriage and dementia is limited with no studies dedicated to marriage commitment and dementia care, although commitment has been identified in some studies as the most significant factor in long-term marriages. Recently there has been a call for a more empowering inclusive vision for dementia care - towards a relationship-centered approach. The current study focused on a relationship-centered approach, and on enduring commitment as the thread woven together creating patterns of caring that helped sustain dementia care. The conceptual model delineated, examined the

marital biography and its impact on the dementia experience (refer to Figure 6, p. 133). A conceptual model was formulated which identified the process of the influences in the commitment cycle (refer to Figure 8, p. 166). Contributing factors to commitment that formed the bases for patterns of caring were outlined (refer to Figure 11, p. 249). In the conclusion, the three above-mentioned figures were combined to reformulate an integrated model (Figure 12, p. 266) to illustrate the enactment of commitment to the marriage relationship on the dementia experience.

The conceptual model (Figure 12, p. 266) deduced from in-depth narrative accounts of the respondents and serves as a useful process for understanding: (1) the commitment factors in marriage that enabled couples to accommodate the dementia experience in the early stages, and (2) the notion of "us with a future" as living-in-relationship. Although the model suggested here requires further investigation before it can be applied more widely, it nevertheless provides useful insight into how the study group of couples in the early stage of dementia began to make sense of the situation and integrate it into everyday life. Future studies could attempt to explore how this suggested model differs for couples in short-term marriage relationships and different cultural groups. As well, variations between people with dementia and their partners could be explored in future studies (Robinson, Clare, & Evans, 2005, p. 344). The processes identified in the above mentioned model are useful for future research on the impact of the marital relationship on Alzheimer's disease, and how it is connected to the care context. Future analysis should include the perspectives of both the caregiver and receiver in the early stages of Alzheimer's disease. This study illustrates the importance of conducting exploratory qualitative research in marriage and dementia where concepts such as commitment and forgiveness are not well defined.

Implications of my study for the study of marriage and dementia

Research into the understanding of couples with spouses in the early stage of AD will become vital suggests MacQuarrie (2005), as researchers, the pharmaceutical industry and health systems, develop, promote, and distribute drugs to slow down the progression of Alzheimer's disease and maintain people in the early stages to mid-stages for prolonged periods (p. 439). Maintaining people in the early to mid-stages for prolonged periods with drugs will have a significant impact on the health care system, home care, social work service and nursing care. Couples will be able to remain at home, together, for longer periods of time, and will expect programs and support services to accommodate their ongoing needs. If we are to successfully assist with accommodating these needs, we will need to consider couples who demonstrate commitment to their marriage relationship as "partners" with the health care system. Couples will take on a high level of care. The onus is on the health care system to become sensitive to and support commitment so there will be less of a care component and less dependency on institutional care. Dependence on health care usage is generally more of an exception than the rule, and relates to the level of commitment and willingness to care. This opens the door to another level of study. Where are couples along the continuum of commitment to care? This has implications for the use of health and social care. Less commitment might suggest more care from outside the home will be needed. It is important to identify as early as possible, at time of diagnosis of early stage dementia, what level of commitment couples have to their marriage relationship and what commitment means to the future of their relationship in their socio-cultural context. Understanding a couples' socio-cultural context means understanding a shared

perspective that contributes to shared values and beliefs that act as a guide for decisions made about future caring.

A recent article articulates the need to develop a research agenda for broadening the vision of dementia care that includes the socio-cultural context (O'Connor, Phinney, Smith, Small, Purves, Perry, Drance, Donnelly, Chaudhury, & Beatty, 2007). The socio-cultural values, norms, beliefs, and assumptions about marriage shaped how marriage and the dementia experience were interpreted and responded to by all spouses studied. Their belief in the moral sanctity of the traditional marriage, with the assigned roles and responsibilities, was engrained into their "us identity." The current findings suggest family history is important as couples modeled the positive attributes, of their parents' marriages and recognized they hade passed those attributes such as reciprocity, resilience, and forgiveness on to their children as well. Family history was important for another reason. Several of the study couples had a history of dementia in the family and were familiar with the progression of the symptoms and what to expect down the road. They also expected their children would provide support in the future, just the way they supported their own family members with dementia. It would be considered their duty.

The study through narrative analysis of the couples' stories pointed to a number of interesting findings relevant to further research. This and similar studies suggest lifetime commitment to marriage to be the essence of couple' long-term marriage relationships. Commitment to each other helped sustain each couple early on during tough times and hard work, during the middle years, doing things together and working through difficulties and the later years, being there for each at during the dementia experience with the resulting changing roles, responsibilities to their relationship, and the

drifting away of friends. Couples were highly committed to the future of their relationship, vowing to "hang in as long as possible" together at home.

Spouses in the current study strived to maintain continuity to their lives and continued with the established patterns of caring by letting their spouses do as much as they could under supervision. They were resilient to the changes experienced as a result of early-stage Alzheimer's disease with a lifetime of accommodating change with changing circumstances. The couples maintained continuity through forgiveness, by letting go of past difficulties and presenting a united front, an edited version of their lives together, with the exception of Gladstones who held on to a few past issues with a vengeance.

The anticipated care needs of the future were unknown except for the need expressed by the Peters and Smiths to move closer to their children for support. Perhaps the research couples felt supported by the research team monitoring the clinical drug trial participants. Enrolling in this clinical drug trial was a significant event for my research couples. What is missing from the research is the impact of the experience on the couple.

The current trend in medical research on Alzheimer's disease focuses on early detection (Beard, 2004). This emphasis on early detection and disclosure of a diagnosis of dementia highlights the need to examine a couple's shared construction of, and response to, the diagnosis early on in the process of the disease (Robinson, Clare, & Evans, 2005). According to Solomon and Murphy (2005), less than one-half of all Alzheimer's disease patients are currently diagnosed and approximately 25% are treated with anti-dementia drugs. Most clinical investigators involved in drug trials believe that by the time the clinical diagnosis of Alzheimer's disease has been made enough damage to the neurons of the brain would prevent reversal of the condition (Peterson, 2003). The

focus instead is on secondary prevention treatment trials involving minimally symptomatic individuals with mild cognitive impairment of early Alzheimer's disease.

Implication of the study for social work practice

The analysis of the couple's narratives demonstrated that commitment-based relationships are adaptable to changing circumstances. Partners collaborate to address their challenges in the early stages of dementia and later with the diagnosis of early-stage Alzheimer's disease. Dementia changes the context and content of the relationship but the partners' adaptation to the relationship is undisturbed. Social workers and external caregivers should recognize the continuing strengths of the dyad's relationship and also consider the possibility that marriages may be fraught with "trials and tribulations" and some may be characterized as unhealthy, and lack commitment. Ongoing support such as a home safety program, behavior and communication techniques, and referral to a support group could be helpful in the earlier stages. With the progression of the disease, and the changing ability to accommodate change within the couple, programs such as respite and day care services could be helpful.

Research participants accommodated change during changing circumstances throughout married life based on patterns of caring that included: doing things together, reciprocity, resilience, and forgiveness. These patterns of caring represent many of the salient principles of the "Strengths Perspective" in social work practice. The Strengths Perspective holds that all people have strengths, people need to have a sense of belonging and social support, people are resilient and reciprocal relationships are necessary for people to gain a sense of belonging and membership (Saleebey, 2002). The Strengths

Perspective is an excellent lens to providing assessment, intervention, and evaluation services and programs to help families encountering dementia face the future.

The current study suggests couples in the early stages of Alzheimer type dementia wanted to know the diagnosis, were interested in participating in a clinical drug trial, and wanted to be included in the plan of care making decisions "together" for their future. A recent study on dyadic interventions in early-stage dementia supports they findings (Whitlatch, Judge, Zarit, & Femia, 2006). Findings suggested spouses diagnosed with AD were able to enter into a dialogue about the meaning of dementia symptoms in their lives, and I believe appreciated talking about it to me. Although each couples roles' and responsibilities changed as a result of dependency and loss, they did not express burden or stress in their narratives. Current research is now focusing on the strain and gain of caregivers of individuals with Alzheimer's disease. In other words, "Is the glass half empty or half full' (Sanders, 2005). Clinical gerontological social work practice based on the "Strengths Perspective", needs to further examine the positive aspects of gain associated with the caregiving role (p. 72).

Jane Gross from the New York Times ran an article on March 29, 2007, titled *Living With Alzheimer's Before a Window Closes*. The article reports on innovative early stage services at the New York Alzheimer's Association chapter that addresses the imbalance of services. Early stage patients now have services such as access to a joint support group and a speakers' bureau, and have become popular speakers at national conferences and persuasive lobbyists with state and federal lawmakers. Out of their frustration, Gross reports, patients are creating a grass-roots movement to improve services and change public perceptions.

Social work with elders is considered one of the "hottest" areas of social work practice in the new millennium according to McInnis-Dittrich (2002). As an increasing proportion of the Canadian population lives to a very old age, the incidence of dementia of the Alzheimer's type is projected to increase dramatically. Social workers who work with persons diagnosed with dementia and their families and the community, in one or more of the many roles of counsellor, case manager, group worker, advocate, enabler, educator, mediator, or outreach worker will be called on for practice expertise in the field of gerontology. Frameworks for health and social service delivery that include a relationship-based model emphasizing socio-cultural understandings are needed (Pratt, Clare & Kirchner, 2006: Mahoney, Cloutterbuck, Neary, & Zhan, 2005), as well as skillful individual assessments (Nolan, Grant, Keady, 1996). The significance of this study for social work is that it integrates concepts of relationship-centered care into a conceptual model of commitment to the marriage relationship and the dementia experience. The significance of considering the marital dyad living-in-relationship with respect to dementia is (1) a potential sentinel of couple strengths and limitations in encountering other life challenges to ascertain capacity to care (2) an indicator of areas in the marriage biography that could form the basis for problem identification and thus a counselling plan, and (3) a gauge of possible outside support to sustain the couple.

Limitations of the study

It is important to highlight some of the limitations of the study. The sample size was small. The study participants were highly selective and were comprised of couples who were able to access a diagnostic testing clinic and who were eligible to participate in a clinical drug trial. All respondents were Caucasian, middle to upper class. However,

they did have a range of education, and one couple was limited in their ability to articulate their experiences. The selection criteria had to include both spouses being willing and able to participate, and it took close to one year to recruit all six couples. Three other couples were referred, but in each situation the caregiver refused. It may be that couples who want to participate in research are more likely to articulate positive aspects of experience than those who refuse. In order to conduct research studies with early stage Alzheimer's disease spouses you need a sample of persons who have received a diagnosis of probable Alzheimer's disease, and high enough in verbal functioning to participate in the interviews. Although all spouses were for the most part able to articulate one spouse felt frustrated at not being able to get her thoughts out. In this situation I have a joint narrative reflecting more of one spouse's perception of the impact of commitment than a joint narrative of meaning to the marriage relationship.

It is also important to note that the interview process may have created a situation where people provided a positive view of themselves as a couple and minimized the negative aspects of their relationship. The study reflected only what couples wanted and did tell me about their relationship.

All couples had the support of the specialized memory clinic staff that included a nurse and neurologist. As well, the couples attended monthly visits together to assess how things were going. Couples not involved in a clinical drug trial seldom have such sophisticated attention. A limitation here is that a social worker was not a member of the clinic team.

The quantitative scales were useful to the study in combination with the interviews. Triangulation occurred through global, local and themal coherence of the interviews to the scale results. However, the scales posed a problem for two couples. The

spouse diagnosed with Alzheimer's disease in both situations was not able to fill the questionnaire out on his or her own, in part because the questions were confusing and the rating scale terrifying. Each of the two couples chose to answer the questionnaires together. In responding to the questions, I found the spouse with dementia often succumbing to the voice of the caregiver.

The trustworthiness of the research project in general was validated by the fact that the couples' neurologist referred them to me and I had worked with him in the past at a memory assessment clinic as a clinical social worker. Thus the project was deemed trustworthy in the neurologist's and the families mind. It would have been difficult to recruit my participants without the support of the memory clinic, and more specifically the director's enthusiasm for the project. The couples were vulnerable and suspicious of inappropriate research goals as Alzheimer's disease is marketed in inaccurate ways to reflect magic cures and unauthorized over the counter drugs. However, the couples had just recently agreed to the drug trial and were hopeful for relief from the symptoms of Alzheimer's disease.

Conclusion

A few years ago I was a practicing social worker and manager of a memory assessment clinic. Unfortunately, funding was promised for a two and a half year time period only. At the end of that period, funding ended and the clinic closed. I had earlier suggested a role for social work in memory clinics, and in many clinics throughout the world social work does have a significant role. After undertaking this study, and keeping abreast of the literature and practice initiatives (as far as possible with the plethora of available journals), it is my observation that the role of social work has not advanced as

quickly as the number of memory clinics has. With the focus now on early diagnosis and early stage services for Alzheimer's disease, it seems important to me that social work play a key role in the design and delivery of those services.

The development of the model presented in the study, reflects a gap in understanding how a couple's commitment to their marriage, and patterns of caring throughout their relationship-biography impacts the dementia experience and willingness to provide care at the time of a diagnosis. I am under no illusion that many challenges lie ahead in developing the model presented in my study. However, if this orientation of marriage commitment and the dementia experience is seen as meaningful, and the findings are used to influence practice, then the project will have been worth the effort.

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Appendix A

LETTER OF INVITATION TO CLINIC DIRECTORS AND PHYSICANS FOR RECRUITMENT OF SAMPLES

Dear (Director),

Re: Recruitment of sample for a dissertation research on "*Impact of Commitment of the Marriage Relationship on the Dementia Experience*"

I would like to request your help in recruiting married couples where one of the spouses has recently (3 to 6 months) been diagnosed with dementia of the Alzheimer's type in the early stages, as research participants for my study. I will examine the influence of commitment to the marriage relationship and the experience of dementia. The present research is a partial fulfillment for my Ph.D. in Social Work at the University of Manitoba.

My sample criteria are that married couples are:

(1) Heterosexual couples in a marriage considered 'long-term' (20 years or over).

(2) One of the spouses is diagnosed with early stage Alzheimer's type dementia;

(3) Able to use English as their main language.

The research will take place at three home visits:

Home visit #1 – During home visit #1, three questionnaires will be administered to each spouse: (1) The Dyadic Adjustment Scale (2) The Role Orientation Subscale of the Marital Satisfaction Inventory and (3) Commitment to the Spouse. The home visit is expected to last for approximately 1 ½ hours.

Home visits #2 and #3 – At home visits #2 and #3 tape recorded in-depth interviews will take place with the couples jointly. Each of the interviews will take approximately 1 ½ hours.

I request ongoing discussion with your contact staff regarding selection of samples during my interview process from January, 2006 to March, 2006.

All couples' participation is voluntary. Privacy and confidentiality are guaranteed. I shall be responsible for informing potential participants of the benefits and risks of participation in the study. The data collection procedure is approved and scrutinized by my dissertation committee and the Ethics Review Committee of the University of Manitoba. Whenever I use the materials I collect of the couples, I will not use their names or any other identifying information. Discreet quotes from respondents and interpretive statements will be available for participants' comments. Interviews with participants will be recorded by audiotape for the purpose of analysis. They can ask that the audio recorder be turned off at any time during the interview process. The tapes of the interview

and their transcripts will be stored in a locked file kept safely in my office and I am the only one who will have access to them. The tapes will be erased upon completion of the study.

Your help in this study will greatly enhance a deeper understanding of how couples enact their marriage commitment in the midst of a diagnosis of dementia. With an increasing number of couples facing dementia in Canada, my study of commitment in marriage will illuminate the strengths and difficulties couples face to advance dementia support programs and family policies.

I look forward to discussing my proposal with you in further detail. I hope the results will be of use to your clinic and I will share my findings in any way that is helpful. For any inquires, please contact me at (phone number) or Dr. Don Fuchs, my supervisor, at (phone number).

I look forward to hearing from you. Thank you.

Sincerely,

Judie Davies, Ph.D. (Candidate)

Contact Information Slip

This is not a consent form. By completing and returning this form, you are only giving permission to be contacted and to receive more information about the research project.

Project title: ***Impact of commitment to the marriage relationship on the dementia experience***

I would like more information about this study.

Please:

Call me.
Phone:_____

Best time to call:_____

Or

Mail the project information to me.

Address:_____

Postal Code: _____

_____ _____
Please print your name. **Signature**

Please return the completed form in the enclosed stamped envelope.

To: Judie Davies
(address and phone number)

Appendix B

INTODUCTION LETTER TO COUPLES

Dear Married Couple:

You requested more information about a study on *Impact of commitment to the marriage relationship on the dementia experience*. I am writing to inform you of that project and to ask you to consider participating in the study. The research is a partial fulfillment for my Ph.D. in social work at the University of Manitoba.

Your help in this study will greatly enhance a deeper understanding of how couples enact their marriage commitment in the midst of a diagnosis of dementia. With an increasing number of couples facing dementia in Canada, my study of commitment in marriage will help illuminate the strengths and difficulties couples face to advance dementia support programs and family policies.

My sample criteria are:

(1) You are a heterosexual couple in a marriage considered long-term (20 years of more);
(2) One of you is diagnosed with early stage Alzheimer's type dementia;
(3) Both of you are able to use English as your main language.

There will be three home visits lasting approximately 1 ½ hours each. The purpose of the first visit is to talk about the project that including the benefits and risks. I will ask you to read over the consent form, and you may ask any questions about the study. If you are interested I will ask you to sign the consent form. There will be three brief questionnaires for each of you to complete, one about marital satisfaction, another about gender role in marriage and another about commitment.

The second and third home visits will consist of a taped interview with both of you about your "marriage story." I will ask questions like "Tell me about when you met and married" and "What are your roles and responsibilities in the marriage?" Your participation in the study is voluntary. Privacy and confidentiality are guaranteed.

I look forward to discussing my study with you in detail in the future. I will be able to share my findings with you if you would like. If you are interested in participating in this project, please call me at (phone number). I look forward to hearing from you.

Sincerely,

_____

Judie Davies, Ph.D. candidate
Date and Address

Appendix C

Project Description and Informed Consent to Participate

Research Project Title: *Impact of Commitment to the Marriage Relationship on the Dementia Experience*
Researcher: Judie Davies
Research Supervisor: Dr. Don Fuchs

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 carefully and to understand any accompanying information.

I am a graduate student at the University of Manitoba. I am requesting your participation in my research on the influence of commitment to marriage vows or promises before and after a diagnosis of dementia, which is a partial fulfillment for the Ph.D. in Social Work. The purpose of the study is to identify differences and similarities in commitment. Using in-depth interviews, I am interested in hearing your story of being a couple and how you have experienced dementia.

In the first phase of the research design, I will use a marriage questionnaire to identify a small group of long-term married couples for further interviews. I will invite you to fill out the questionnaire individually. The approximate length of time for the first home visit is approximately 1 ½ hours. I will invite you to participate in the second phase consisting of two in-depth joint interviews with you and your spouse. The length of each interview is approximately 1 ½ hours. If I have further questions during my analysis, I may contact you for a further interview.

Participation in this study is voluntary. Declining to participate will have no negative consequences.

Your participation in the study will greatly enhance a deeper understanding of how couples enact their marriage commitment in the midst of a diagnosis of dementia. With an increasing number of couples facing dementia in Canada, my study of commitment in marriage will illuminate the strengths and difficulties couples face to advance dementia support programs. After your experience of twenty years or more of your marital life, I believe both pain and joy will be touched on in the interviews. There may be recall of unhappy experiences in your marriage. If there is disclosure of abuse, I am obligated to report this to your family physician. If you have any upset feelings after the interviews, you can contact me for information about counselling that is available in your community.

The interviews will be recorded by audiotape for my analysis purpose. You may ask that the audio recorder be turned off at any time during our discussion. The tapes of the interview and their transcripts will be stored in a locked file kept in my office. The tapes will be erased upon completion of the study. The research records will be kept strictly confidential and stored separately from the consent forms. Discussion of the interview materials is solely for my learning purpose with my dissertation supervising committee members. In any publications, I will not quote your names or any identifying information, to ensure anonymity. I may use the results of the study in a journal article or a presentation. I assure that confidentiality will be maintained in every way possible. Direct quotes, together with my interpretive statements, can be reviewed by you before they are published.

Since the study highly honours your role of participation as my collaborator, I am ready to hear your feedback at any time and welcome your comments of my analysis of findings which will be available by late 2006. Please indicate whether or not you wish to receive a summary of the study by surface mail, by December 2006. After this research is completed and the thesis is accepted by the thesis committee, the transcripts of interviews and the consent forms will be destroyed. The approximate date by which all data will be destroyed is March 2007.

I wish to receive a summary of the study by surface mail Yes___ No___

There is no payment or cost for participating in this study.

Signing this Project Description and Consent Form indicates that you have understood to your satisfaction the information regarding participation in the research project. In no way does this waive your legal rights or release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the project 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.

Principal researcher: Judie Davies, Phone: (phone number)

Supervisor: Dr. Don Fuchs, Phone: (phone number)

This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project, you may contact either of the above-named persons or the Human Ethics Secretariat at (phone) or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

_____

Participant's Signature Date

_____

Researcher/Delegate's Signature Date

Appendix D

RECRUITMENT SCRIPT

Thank you for your interest in finding out more information about the research project on Commitment in marriage and the dementia experience. My name is Judie Davies. I am a student in the Ph.D. program in social work at the University of Manitoba, and I will be conducting the study as part of my degree requirement.

The first thing I want to talk to you about is your consent or agreement to participate in the project. Both of you will need to consent separately. What I will do is have you read over the consent form carefully to make sure you understand what is involved in agreeing to participate in the project. If you have any questions we will discuss them. I will ask you both a couple of questions about your understanding of the project. If I believe that either one of you is not clear about the research purpose or process, I am obligated to not consider you for the project. If either one of you do not want to proceed, you have the right to say so. If one of you does not want to proceed you will not be recruited for the study.

I will inform your husband's/wife's doctor of your willingness to participate if we agree to proceed to ensure he/she has no concerns. After the consent forms have been signed I will ask you to fill in some information about yourself, such as your age, and if you have any children. Next I will ask you to fill out two questionnaires about your marriage.

At the end of the visit we will set up a convenient time to meet for the second home visit. At that visit I will interview you together.

Appendix E

MARRIAGE QUESTIONNAIRE

Husband / Wife

- The following is a questionnaire on your views about your marriage.
- There are no right or wrong answers. Please √ the most appropriate column for you in each of the following questions.

Within your marriage please indicate the extent you agree/disagree on these items.

	Always agree	Almost always agree	Occa-sionally disagree	Frequently disagree	Almost always disagree	Always disagree
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstration of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behavior)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure-time and interests and activities						
15. Career decisions						

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Within your marriage please indicate the extent you agree/disagree on these items:

	All the time	Most of the time	More often than not	Occa-sionally	Rarely	Never
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
17. How often do you or your mate leave the house after a fight?						
18. In general, how often do you think that things between you and your partner are going well?						
19. Do you confide in your mate?						
20. Do you ever regret that you married (or live together)?						
21. How often do you and your partner quarrel?						
22. How often do you and your mate get on each other's nerves?						

	Every day	Almost every day	Occa-sionally	Rarely	Never
23. Do you kiss your mate?					

	All of them	Most of them	Some of them	Very few of them	None of them
24. Do you and your mate engage in outside interests together?					

How often would you say the following occur between you and your mate:

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas						
26. Laugh together						
27. Calmly discuss something						
28. Work together on a project						

There are some things about which couples agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. Please check yes or no.

	Yes	No
29. Being too tired for sex		
30. Not showing love		

31. The dots on the following line represent different degrees of happiness in your relationship. The point, "happy", represents the degree of happiness of most relationships. Please circle the dot that best describes the degree of happiness, all things being considered, of your relationship.

- **Extremely unhappy**
- **Fairly unhappy**
- **A little unhappy**
- **Happy**
- **Very happy**
- **Extremely happy**
- **Perfect**

32. Which of the following statements best describe how your feel about the future of your relationship: Please circle the number

5 I want desperately for my relationship to succeed and would go to almost any lengths to see that it does.

4 I want very much for my relationship to succeed and will do all that I can to see that it does.

3 I want very much for my relationship to succeed and will do my fair share to see that it does.

2 It would be nice if my relationship succeeded, and I can't do much more than I am doing now to help it succeed.

1 It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

0 My relationship can never succeed, and there is no more that I can do to keep the relationship going.

MARRIAGE QUESTIONNAIRE

Husband / Wife

- The following is a questionnaire on your views about your marriage.
- There is no right or wrong answers. Please √ the most appropriate column for you in each of the following questions.

Within your marriage please indicate the extent you agree/disagree on these items.

	Always agree	Almost always agree	Occa-sionally disagree	Frequently disagree	Almost always disagree	Always disagree
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstration of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behavior)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure-time and interests and activities						
15. Career decisions						

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	True	False
18. It's only natural for a man to be bothered if his wife makes more money than he does.		
19. Most women are better off in their own home than in a job or profession.		
20. A woman should be able to choose a career outside the home just as her husband does.		
21. A wife should not have to give up her job when it interferes with her husband's career.		
22. A wife's career is of equal importance to her husband's.		
23. Where a family lives should depend mostly on the husband's job.		
24. A woman should take her husband's last name after marriage.		
25. Basically, most men still desire nurturing and "traditional" women.		

The End

☺

Thank you very much for your cooperation!

Appendix G

Commitment to the Spouse

Why did you marry?

Why have you stayed married to your spouse?