

**Commitment and the marriage relationship:  
The dementia experience**

**by**

**Judith C. Davies**

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**Commitment and the marriage relationship: The dementia experience**

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**Judith C. Davies**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of  
Manitoba in partial fulfillment of the requirement of the degree**

**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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Judie Davies  
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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 & Anshensel, 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 historicize 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.

Brodsky, 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.